Patient Journey from Hearing Aids to Cochlear Implant: A Retrospective Study

Natasha Kate de Jongh

A thesis submitted in partial fulfilment of the requirements

for the degree of Master of Audiology

School of Psychology, Speech and Hearing

University of Canterbury

May 2020

Abstract

Aims: This study was conducted to develop a better understanding of the transitional journey from hearing aids (HA) to receiving a privately funded cochlear implant (CI) in adults with postlingual hearing impairment (HI), to determine the sources of funding for the CI and corresponding rehabilitative treatment and to establish if individuals who privately funded their CI have similar outcomes to those who have them publicly funded.

Methods: Semi-structured interviews, developed from the life adjustment model were conducted with 12 privately funded CI users. Interviews were transcribed and thematically analysed to find common themes and sub-themes. The Nijmegen Cochlear Implant Questionnaire and AQoL-6D were used to help support the interviews findings.

Results: Within the four stages (Before Rehabilitation, During Rehabilitation, After Rehabilitation and Throughout Journey), a total of 24 themes were identified. Each theme had between 1 to 12 sub-themes. This thesis found that participants were struggling and believed a CI was the only option forward. Overcoming the substantial cost was the most common barrier in their journey. Although the adjustment after implantation was challenging, participants collectively had a positive outlook towards CIs along their journey. The abundance of sub-themes highlighted the diversity in each participant's journey.

Conclusions: Due to the absence of qualitative research in New Zealand (NZ) studying CI users, there is a need for more research to be conducted in this field. The findings highlighted the persistent concern that public funding for CIs in NZ is not adequate. An increase in public funding and/or alternative funding methods should be considered. The importance of patient-centred care is apparent, it is advised that hearing professionals keep up to date with information that can assist them in providing a higher level of care.

Keywords: Cochlear implant, hearing impairment, hearing aids, patient journey, adults

Acknowledgements

I would like to thank and acknowledge my supervisory team, Rebecca Kelly-Campbell and Valerie Looi. I greatly appreciated your guidance, critique, expertise, patience and understanding.

An enormous thank you to all the wonderful individuals who participated in this study. For being so generous with their time and being so willing to share their stories. I appreciate those who travelled to meet with me at the university campus, and those who welcomed me into their homes. Without you, this research would not have been possible.

To Advanced Bionics (Sonova), without your contribution of funds and continued support, this study would not have gone ahead. I greatly appreciate the experience that your contribution enabled.

I would like to thank the cochlear implant programmes within New Zealand who assisted me with recruitment and helping answer many of my questions.

I thank my parents for the financial and emotional support. It was a rough year. Without you none of this would be possible. You have always had my back, with whatever I have pursued. I will pay you back one day! I promise.

Lastly, to all my friends. To those who have known me for years, and to those I have made during this course. You have always been so willing to help me out, even if it is last second. Thank you all for being so kind, supportive and welcoming. I will miss having you around, but the messenger group chat will live on.

Table of Contents

List of Abbreviations

ACC - Accident Compensation Corporation

ANOVA - Analysis of Covariance

AQoL- Assessment of Quality of Life

CI – Cochlear Implant

CNC – Consonant Nucleus Consonant

CT – Computerised Tomography

GDC - Geriatric Depression Scale

GLM - general linear model

HA – Hearing Aid

HHIE-S - Hearing Handicap Inventory for Elderly

HI - Hearing Impairment

HINT – Hearing in Noise Test

MoH – Ministry of Health

ICF- International Classification of Functioning

MRI – Magnetic Resonance Imaging

NCIQ -Nijmegen Cochlear Implant Questionnaire

NZ – New Zealand

QALY - Quality Adjusted Life Year

QOL - Quality of Life

SNHL - Sensorineural Hearing Loss

ST – Scala Tympani

SV – Scala Vestibuli

UK – United Kingdom

USA – United States of America

WHO - World Health Organisation

List of Figures

List of Tables

Introduction

Hearing and Hearing Impairment Overview

For a human to detect a sound, a complex system of anatomical structures within the external, middle and inner ear propagate and process a vibration (acoustic wave) that is converted into an electrical signal which is interpreted by the brain as sound. When any part of this system is compromised, a hearing impairment (HI) can be experienced.

Prevalence. Information surrounding the prevalence of HI is scarce with very few studies being carried out measuring representative population samples. The data also varies with how hearing impairment is reported and measured. This means unifying the data and drawing conclusions is more difficult. Current data suggests that HI affects approximately 6.1% of the world's population, 93% of them being adults. One third of adults over the age of 65 are affected by a disabling hearing loss (World Health Organisation, 2018) and newer estimates from the World Health Organisation estimate 466 million people worldwide have a disabling hearing loss (World Health Organisation, 2019). The Global Burden of Disease Study concluded that hearing loss was the fourth leading cause of disability globally and that the prevalence of hearing loss doubles with every decade increase in age (Vos et al., 2016). Approximately half of severe-to-profound hearing loss was presented in children/from birth while the other half of severe-to- profound loss was developed in adulthood (Mathers, Smith & Concha, 2000).

Types of hearing impairment. HI is defined as one of three types; conductive, sensorineural or mixed. Conductive hearing impairment involves the outer or middle ear whereas sensorineural hearing loss (SNHL) involves the inner ear or a retrocochlear pathology. Mixed HI is a combination of the previous types mentioned. Depending on where the site of lesion is, the effects of hearing loss on the individual can be different, and their treatment options differ. For instance, SNHL is caused most commonly by the death of outer

and/or inner hair cells. This can cause issues with a decreased dynamic range and cause more distortion than a normal hearing person would experience (Bernstein, Summers, Grassi & Grant, 2013). HI can be classified at various degrees. One of the most commonly used today was developed by Goodman (1965). Goodman's table allowed hearing loss to be categorised at different severities ranging from normal at <25 decibels to the upper limit called profound hearing loss at >90 decibels.

Effects of Hearing Impairment

Social isolation. With approximately half of severe-to-profound hearing loss developing in adulthood (Mathers et al., 2000), the outcomes for those who experience a significant decline in hearing can be dramatic in many aspects of their life. Hearing loss in adults largely affects their ability to communicate effectively and hearing loss can cause some adults to socially isolate themselves. Mick and Lin (2013) indicated that older women are the largest population that experiences social isolation due to hearing loss. It is also suggested that the extent of hearing loss correlates with the amount of social isolation experienced. There were also some interesting associations between hearing loss and reduced emotional and financial support with women in this age group. The authors concluded that HI might be substantially impacting on health and wellbeing than previously thought (Mick, Kawachi & Lin 2014).

Mental health and physical health. Social isolation is not the only negative outcome of hearing loss. Research has suggested that individuals can experience depression, loneliness and lower self-esteem (Jerger, Chmiel, Wilson, & Luchi 1995; Wallhagen, Strawbridge, and Kaplan 1996). Cosh et al. (2018) revealed that individuals experiencing mild-to-severe hearing loss have significant correlation with depressive symptoms, but no correlation with an incident diagnosis of depression. Some individuals with hearing loss experience negative consequences in their interpersonal relationships due to their inability to communicate

effectively (Smith & Kampfe, 1997). However, many of these negative outcomes that have contributed to hearing loss are comorbid with other factors that occur with aging and might not be the sole cause of some individuals' negative experiences (Strawbridge, Wallhagen, Shema & Kaplan, 2000). They concluded that there were increased problems with mental, physical and social health over the year the study monitored in the hearing-impaired population when compared to those who reported no HI. They also acknowledged that there was a dose-response pattern; the more HI, the higher instance of problems. This study concluded that HI is independently associated with a decline in a broad range of functional outcomes.

Cognition. Hearing loss is suggestive of increased cognitive decline, however concluding if hearing loss is a direct contributing factor or declines alongside cognition is still up for contest (Dawes et al., 2015). The first hypothesis is that hearing loss and cognitive decline have the same neural degradation pathway and therefore are often correlated, but potentially not causal (Lindenberger & Baltes, 1994; Baltes & Lindenberger, 1997). The second is the cascade hypothesis which involves a causal relationship between auditory deprivation and loss of cognitive ability. This hypothesis suggests that long term auditory deprivation causes worsening cognition directly or via the effects that hearing loss has on social isolation and depression (Lin et al., 2013; Wahl & Heyl, 2003). Hearing loss and social isolation have been shown to be independently linked (Gates & Mills, 2005) and social isolation and decline in cognition has also been independently linked (Plassman, Williams, Burke, Holsinger & Benjamin, 2010). Therefore, there is evidence suggesting that hearing loss that causes an individual to be less likely to socialise is what causes cognitive decline (Dawes et al., 2015).

In conclusion, HI affects a multitude of areas within a person's life. In some cases, there is a direct causative relationship with negative experiences i.e. social isolation. Other

negative outcomes linked to HI could be formed by a more complex cascading effect i.e. neural degenerative disease. These negative consequences of HI can greatly affect an individual's quality of life (QOL), especially when left unmanaged and unsupported.

Hearing Aids, Benefits and Limitations

A common treatment option for individuals experiencing HI is the provision of hearings aids (HA). The benefits of HA have been largely explored and documented. Studies have revealed that HA have provided sustained increase in QOL for those experiencing HI by reducing psychological, social and emotional effects of SNHL (Mulrow, Tuley & Aguilar, 1992; Chisolm et al., 2007; Ferguson et al., 2017). After the 1990s switch to digital HA technology, the further advancements in processing of sound information and directional microphone advancements, more recent research indicates that HA do provide improvements in noisy environments and even in very high noise levels (Kuk, Lau, Korhonen & Crose, 2015; Wu et al., 2019). Some research indicates that the improvements in noise provided by directional microphones and noise management algorithms have varying results and are limited in benefit (Magnusson et al., 2013; McCreery, Venediktov, Coleman & Leech, 2012).

Hearing aids for severe-to-profound users. The amount of benefit that HA can provide a wearer with severe-to-profound hearing loss is limited by several things. Due to the smaller dynamic range in listeners with severe-to-profound hearing loss, HA are often fitted with high compression in order to not be uncomfortably loud. Bor, Souza and Wright (2008) showed that when HA had high compression this caused poor spectral resolution and therefore audible identification of vowel sounds was greatly diminished. Byrne, Parkinson and Newall (1990) suggested that there is a risk of potential over-amplification when fitting severe-to-profound hearing losses as many of these individuals need more amplification than what is recommended by National Acoustic Laboratory procedure. Therefore, there is a fine line between providing adequate audibility and over-amplification (Jorgensen, Benson &

McCreery, 2018). Although HA have many benefits for those with HI, these benefits are largely seen in the mild to moderate hearing loss population. Lupo, Biever and Kelsall (2019) measured both subjective and objective variables and concluded that individuals with moderate sloping to profound SNHL do not gain enough effectiveness from HA and strongly recommend cochlear implant (CI) referral. Montes et al. (2017) revealed that CIs are more cost effective for those with profound deafness when compared to HA. They concluded that cochlear implants are the most efficient and effective for improving patient's productivity and QOL in profoundly deaf individuals. Some people, many of whom have severe-to-profound hearing loss, will benefit more from a CI in comparison to HA (Budenz et al., 2011). When individuals no longer benefit from HA, cochlear implantation should be considered. CIs directly stimulate the auditory nerve. Therefore, damage to the hair cells within the cochlea is bypassed.

Cochlear Implants Overview: The Device and Factors Effecting Outcomes

History and development of cochlear implants. As mentioned previously, individuals with severe-to-profound HI can often experience minimal benefit from HA due to inadequate amplification. In these circumstances a CI can be considered. The first CI was implanted in 1961 and consisted of a single wire electrode placed in the scala tympani (Mudry & Mills, 2013). House and Urban (1973) went on to complete more surgical implantations that were updated and had small arrays of electrodes. Although these electrodes were simple, they showed promising results. The patients had some frequency discrimination and were able to recognise several short words. However, the limitation with these early implantations was the high risk of infection due to a lack of biocompatibility with the materials used. Many of these early CIs had to be removed prematurely. Throughout the following years, the professional community were dubious to proceed with cochlear implantation with many refusing to support their development (Eshraghi et al., 2012). Gifford

et al. (2008) reported that over one quarter of patients with CIs achieved 100% scores on sentence material and requested for more difficult material to be implemented to assess patient performance. These collective findings over several decades helped convince government agencies to fund CI research and paved the way for the modern implants available today. CIs currently have electrode arrays ranging from 16 to 24 electrodes and have had significant advancements in sound processing (Eshraghi et al., 2012).

Functionality of cochlear implants. CIs differ greatly from hearing aids because they do not send an acoustic signal into the ear; CIs require a surgical procedure to place an electrode to bypass most of the ear system and directly stimulate the auditory nerve. Implants achieve this via several main components shown below in figure 1. The external components: (1) one or more microphones that pick up sound in the environment, (2) a speech processor that converts sound into digital information and (3) a transmitter coil that receives signals from the speech processor and converts them into electrical impulses and sits on the skin via a magnet. The internal components: (1) a housing with a magnet and receiving antenna and (2) an electrode array that has a variable number of electrodes that send the electrical signals to various regions along the auditory nerve (National Institute on Deafness and Other Communication Disorders, 2016).

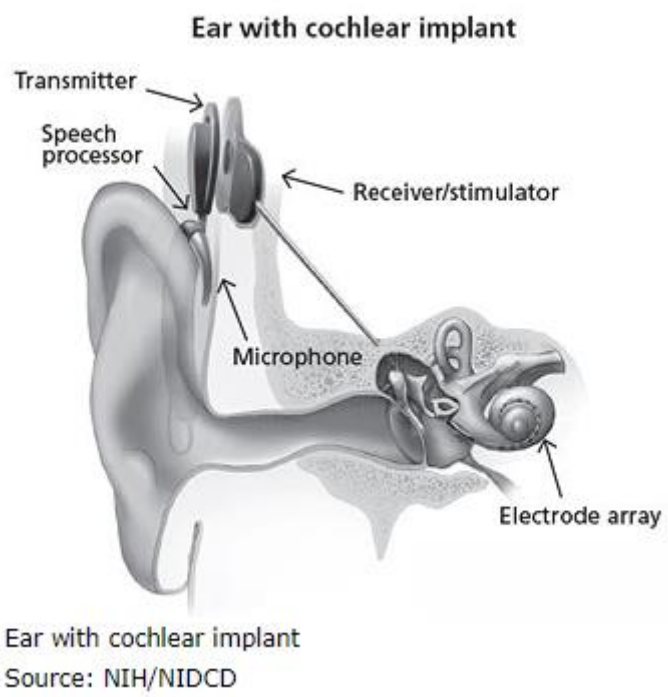


Figure 1 -Ear with Cochlear Implant (National Institute on Deafness and Other Communication Disorders, 2016). Image is not copyrighted, is in the public domain.

Participant variables for cochlear implant outcomes. Many variables have been shown to affect how successful CI outcomes are in QOL measures and speech recognition and perception performance. Participant related factors include: (1) duration of HI, (2) age at implantation, (3) duration of device use and (4) aetiology of HI. Longer duration of HI has been widely shown in the literature to have negative consequences on speech recognition performance in patients with a CI, with duration of severe-to-profound HI having the most influence (Blamey et al., 2012; Holden et al., 2013; Mosnier et al., 2014). Green et al. (2007) examined 117 post-lingually deaf patients and revealed that duration of deafness could be an independent predictor of performance; it accounted for 9% of variability seen in their sample group. Their research showed no significant link between residual hearing pre-implant or age at implantation for predicting CI outcomes. These results are also observed by Budenz et al. (2011). They performed a retrospective study that controlled for duration of deafness which

suggested that older and younger participants benefited equally from their implants. However, some studies' findings have disagreed and found a major factor in outcomes is age at implantation (Blamey et al., 2012; Chatelin et al., 2004; Williamson, Pytynia, Oghalai & Vrabec, 2009). It appears that for adults, the older the patient, the higher likelihood of worse outcomes. The Blamey et al. (2012) study including 2251 post-lingually deaf adults showed age of implantation had a negative influence on speech outcomes for individuals over the age of 70 years.

Another major contributor to success is duration of using the CI. Holden et al. (2013) examined 114 post-lingually deaf adults in the United States of America (USA) who were implanted with a single CI. The participants were segregated into six groups based on their final Consonant Nucleus Consonant (CNC) word score at the end of two years. Their results for CNC words showed by 18 months post activation speech recognition scores peaked for almost all wearers. However, the groups with higher final CNC word scores tended to reach their plateau earlier. Blamey et al. (2012) showed similar results but also indicated that performance improvements can be experienced up to 3.5 years after implantation.

Blamey et al. (2012) compiled data from 2251 post lingually deaf adults from 15 difference centres from around the world to explore factors affecting outcome performance for CI users. Their results indicated that aetiology of HI plays a significant factor in speech scores in quiet (CNC, monosyllabic words, disyllabic words and sentences). Based on the residual percentile rank for each aetiology, on average individuals with sudden idiopathic HI have the best outcomes and individuals with auditory neuropathy spectrum disorder on average have the worst outcomes. Individuals with an undamaged auditory nerve could likely benefit more from implantation and those with malformation or injury to the nerve would likely be less successful and may require auditory brainstem implantation

Device and surgical variables for cochlear implant outcomes. Main device and surgical related factors that affect outcomes are: (1) depth of insertion, (2) location of electrode, (3) surgical approach, (4) device brand and (5) percentage of active electrodes. Surgical success including adequate depth of insertion and angle of insertion also contribute to a patient's success post implantation (Holden et al., 2013; Wanna et al., 2015). Holden et al. (2013) examined the placement of the electrode array using computerised tomography (CT) imaging. They revealed that out of the six segregated groups based on CNC performance after two years, the best groups had majority of the electrodes placed in the scala tympani (ST) with a mean of zero electrodes in the scala vestibuli (SV). The poorer performing groups had a mean of 23.2% of their electrodes in the SV.

Since the collective evidence suggests that electrode placement in the ST provides the best influence on speech outcome measures, Wanna et al. (2014) examined 100 post lingually implanted adults to assess which surgical procedures provided the most consistent placement within the ST observed using CT imaging and best CNC and Hearing in Noise Test (HINT) speech recognition performance. They concluded the highest successful outcomes and ST placement was observed in two surgical approaches round window and extended round window.

Device brands have been explored to show if there are any significant differences on outcomes for participants. Lazard et al. (2012) used the same 2251 participant data pool as the Blamey et al. (2012) study. However, they focused on several different measures. Although they found a statistically significant difference using multivariate general linear model (GLM) analysis ($F = 16.63$, $p < 0.001$) between the performance between brands for speech testing in quiet, this difference between the best performing brand and the worst was relatively minor (14% difference). This same study also showed a relationship between performance outcome and percentage of active electrodes ($F = 17.89$, $p < 0.001$); a rise in

performance was observed when a higher percentage of electrodes were active. Overall there is a multitude of factors that can influence CI outcomes, with many more that were not mentioned above.

Cochlear Implant Process: Candidacy to Switch On

Funding pathways and candidacy criteria. Within New Zealand (NZ) there are several funding pathways for those seeking CIs. Those include public funding via the Ministry of Health (MoH) programme, claiming through Accident Compensation Corporation (ACC) if the hearing loss is caused by an accident or work-related noise exposure, and alternatively privately funded. The minimum eligibility criteria for adults to receive MoH CI funding include; (1) severe to profound hearing loss in both ears (2) hearing is not helped via acoustic methods such as hearing aids (3) have been assessed and are likely to benefit from a cochlear implant (4) must be eligible for NZ publicly funded health and disability services (5) live permanently in NZ, (6) do not qualify for cochlear implant funding through ACC (Ministry of Health, 2015). The Northern Cochlear Implant Programme (NCIP) provide further detail in their adult criteria. They include adult CI criteria is met if the testing shows (1) bilateral moderate to profound sensorineural hearing loss (i.e. ≥ 90dBHL at 2000Hz and above for better ear) including ski slope or reverse losses (2) 60% or less on CVC words in the better ear (Northern Cochlear Implant Programme, 2020).

Cochlear implant process. The candidacy assessment process involves several steps: (1) pre-assessment stage where medical background and hearing history details are gathered; (2) audiology assessment involving check of current HAs and an aided and unaided test battery; (3) rehabilitation assessment involving the discussion of the individuals listening needs and expectations about CIs; (4) Ear Nose and Throat specialist (ENT) assessment that involves discussion about medical history and surgical risk, referral for magnetic resonance imaging (MRI) and/or CT; (5) summary appointment to discuss recommendations (Southern

Cochlear Implant Programme, 2018). Typically, adults are only eligible for funding for one CI, in some cases an adult with a history of meningitis infection might qualify for two implants due to the ossification of the cochlea. Children in NZ are eligible for funding of two cochlear implants if the specialist recommends it (Ministry of Health, 2015).

After being sent a letter with surgical date and operation preparation the surgeon will discuss in more detail the surgical procedure. The operation takes approximately two hours under general anaesthetic and the hospital stay is usually overnight, can be longer depending on the health of the patient (Southern Cochlear Implant Programme, 2018). Roughly three to four weeks post-surgery is the initial switch on and takes between two and three hours to activate and fit the processor. The sound is initially very strange to most users, it takes weeks or months to adjust. Follow up appointments for programming the processor occur over months and years post switch on, starting out with less than a month initially to annually after two years (Southern Cochlear Implant Programme, 2018).

Cochlear implant costs. The expected cost for a single CI in NZ is approximately $50,000 NZD (Bird, 2013; Williams, 2019). A clinical manager from a CI programme in NZ verified this in an email exchange (J. Mustard, personal communication, February 28, 2020), they indicated an approximate figure between $40,000 and $50,000 NZD. The variation is due to the different costs from each of the CI manufacturers, which can vary depending if there are any special offers. The cost includes the device, surgery and follow up for two years. When time comes to upgrade the speech processor, roughly every 6-8 years, it costs approximately $10,000 NZD depending on the manufacture (Bird, 2013).

Objective and Subjective Benefits of Cochlear Implants

Speech testing performance. The cost of the surgery and device need to be justified against the potential benefits the CI may provide an individual. Speech perception test scores have demonstrated the benefit of CIs, when assessed in a clinical situation. Unilateral CI

users perform well in quiet when detecting and recognising sound. However, in noise their performance greatly diminishes. Dunn et al. (2010) studied 60 post lingually implanted adults; 30 with bilateral implantation and 30 with a single CI. They performed multiple speech tests including curving the listener, a multiple jammer test and a cognitive load test. The average improvement for bilateral users were 9 dB, 5 dB and 11dB signal to noise ratio respectively. HINT and CNC word tests also showed average higher scores for bilateral users. Similar results have also been shown in smaller studies (Firszt, Holden, Reeder, Cowdrey & King, 2012; Van Loon, Smits, Smit, Hensen & Merkus, 2017). Gaylor et al. (2013) reviewed 16 studies in the field of unilateral implantation; none of the studies reported a decrease in mean speech scores after implantations, and all comparing pre and post implantation reported statistically significant improvement for mean speech scores. The literature suggests that for unilateral CI users with a HA fitted on the other ear (bimodal), performance is better in speech perception tests than those with just a unilateral CI (Firszt, Reeder & Skinner, 2008; Potts, Skinner, Litovsky, Strube & Kuk, 2009).

Unilateral, bimodal and bilateral fittings. Bimodal users that still have access to low frequencies in the ear opposite to the implant have shown significant benefits to speech understanding. Low frequency sound is important for perceived volume of speech. Most notably, English vowel sounds are prominent in the low frequencies <500 Hz (Ching, Incerti & Hill, 2004; Gifford et al., 2007; Zhang, Dorman & Spahr, 2010). Bimodal benefit has also been documented in noise with various studies ranging in magnitude of benefit (Dorman et al., 2015). The benefit from bimodal fitting also has been shown to assist with objective sound localisation (Ching et al., 2004; Dunn, Tyler & Witt, 2005). However, while the objective measurements for bimodal fittings have been widely researched, there is a lack of evidence from subjective measures supporting these findings. Heo, Lee and Lee (2013) explored the relationships between subjective and objective outcomes for bimodal users.

They discovered that the subjective data largely supports objective findings. They concluded that although the objective benefits were supported, there is a large variability amongst individuals and that audiological rehabilitation needs to be individually tailored.

Berrettini et al. (2011) performed a systematic review of 24 studies that covered clinical effectiveness of single, bimodal and bilateral CI use. Their conclusions were that bilateral implantation has been shown to be the most clinically beneficial for localisation of sound and hearing in noise, with less substantial improvement in quiet when compared to bimodal and unilateral CI. Similar results have been observed in a more recent multicentre randomised clinical trial of 40 individuals (Smulders et al., 2016). Although bilateral CI fittings should not be considered if the user has substantial residual hearing in the unimplanted ear, they should also not be considered if the individual is financially burdened or has other health related complications (Firszt et al., 2008).

Quality of life measures. Whilst there is strong evidence showing the benefit of CI when tested in a clinical situation, real world outcomes and performance and satisfaction outside of the clinic is less well reported. One way of assessing this is QOL questionnaires. The WHO defines QOL as "…an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (World Health Organisation, 2020, para. 1). Cohen, Labadie, Dietrich and Haynes (2004) studied 24 CI users and 27 HA users by sending a pre-rehab (no HA or CI) and post-rehab (with HA or CI) Nijmegen Cochlear Implant Questionnaire and a health related QOL questionnaire. They found no statistical difference between the CI and HA groups and their questionnaire scores post-rehab. Aimoni et al. (2016) evaluated the QOL in fifty-seven over 65-year olds using the Glasgow Benefit

Inventory that had been adapted for otolaryngology. The results indicated an increase in QOL scores post implantation regardless of age or length of auditory deprivation. Overall, the research concludes that QOL and speech perception scores increase post-implantation (Damen, Beynon, Krabbe, Mulder & Mylanus, 2007; Klop, Briaire, Stiggelbout & Frijns, 2007).

Music. One major limitation of CIs that has been explored is the ability to enjoy music; accurate perception of music, and ratings for the sound quality of music have reported poor outcomes and remain difficult for CI users (Limb & Roy, 2014). Bruns, Mürbe and Hahne (2016) studied 105 individuals; 15 pre-CI, 38 post-CI and 52 normal hearing. They measured music discrimination using the MuSIC test battery and access to meaning of music and subjective music appreciation with a music questionnaire. The music appreciation results showed that post-CI users scored the lowest for music appreciation. They also found that music appreciation was independent from music discrimination scores and meaning of music scoring; this finding has also been shown previously (Drennan et al., 2015). Some evidence suggests that despite participants having decreased music enjoyment and listening times post-implantation compared to pre-deafness, they had significantly higher music enjoyment and listening time when comparing post-implantation and shortly before implantation (Looi & She, 2010). Overall the evidence suggests that the sound of music through CIs is subjectively poor and does not provide the user with a pleasurable experience, which could lead to less time listening to music or less time listening to music could lower the ability to perceive and appreciate it. There is some evidence suggesting that music training might have benefits on CI user speech outcomes in complex listening environments and music enjoyment and is recommended as a potential implementation in aural rehabilitation (Looi, Gfeller & Driscoll, 2012).

Patient Journey Model Overview and Applications

"The term 'patient journey' refers to the experiences and processes the patient goes through during the course of a disease and its treatment." (Manchaiah, Stephens & Meredith, 2011, p. 227). Creating a structure for the patient journey and using it to understand common experiences is essential in creating a richer context for interaction between professionals and their patients, and to provide the most appropriate care (Ida Institute, 2020).

Biopsychosocial model. The foundations of various patient journey models begin with the biopsychosocial model. The biopsychosocial model is an approach which considers many factors in health that include; biological, psychological (e.g. thoughts and emotions), and social (e.g. socio-economic and cultural aspects) (Borrell-Carrió, Suchman & Epstein, 2004). It focuses on everything that can contribute a significant role in health, illness and disease, while providing more understanding of the complex external and internal interactions that affect health (Suls & Rothman, 2004). The biopsychosocial model was used to form the World Health Organisation's International Classification of Functioning, Disability and Health model known as the ICF model (World Health Organisation, 2001). The ICF model created a foundation for other models to be created and adapted.

Transtheoretical model and patient journey model. Prochaska and DiClemente (1982) first developed and used the Transtheoretical, or Stages of Change model, to help document smoking addiction and help develop a plan to tackle addiction. This model has since been refined and adapted into several models commonly used today. The Transtheoretical model set a foundation for hearing professionals from around the world to collaborate and develop the Ida Institute patient journey model. This model has undergone changes since the original development and the most current journey stages include: (1) Pre-contemplation, (2) Contemplation, (3) Preparation, (4) Action, (5) Maintenance and (6) Relapse or Permanent Exit (Ida Institute, 2019). A qualitative study of 32 adults with HI in

Wales used the original Ida journey model as a template to develop another model that included the patient's view (Manchaiah et al., 2011). The study used three main stages to develop their patient journey model. The first stage involved the Ida model template to have discussions with the individuals with HI in small groups and from that data, coding and analysis of themes and sub-themes. The second stage involved verifying the themes and subthemes with the participants, ensuring that it represented their journey appropriately. Finally, the third stage compared the Ida model and their findings. The results showed seven main phases. The main difference from the Ida model was the addition of self-evaluation which accounts for patients' consideration of costs, alternative approaches and benefits/disadvantages.

Life adjustment model. The adaptation of the journey model used in this study is known as the life adjustment model which was first developed in a study about women learning to live with chronic pain (Gullacksen & Lidbeck, 2004). This model has three stages: before, during and after rehabilitation. The further development and application of the life adjustment model occurred during a 13 year long longitudinal qualitative study (Gullacksen, 2017). The study included three sub-studies that were conducted in Sweden, across all three studies a total of 77 adults with various levels of HI were interviewed. There results concluded an adaptation to the model and highlighted the need for adopting a patient-centred care approach. Their findings also supported common ideas that were observed in other studies based on the patient journey. For example; HI has a broad range of personal consequences; a correctly fitted HA improved hearing function but some HI related problems still remain. The adaptations to the model included several steps within each stage. The before rehabilitation stage has two main steps: striving back and the tipping point. During rehabilitation includes: mourning, rehabilitation and exploring. After rehabilitation includes restoring and stabilising.

Patient journey model application. Manchaiah et al. (2011) developed a patient journey model that was then used to structure a follow up study addressing the experience of HI (Manchaiah & Stephens, 2011). The study involved interviewing two individuals living in southern Wales. The interview process involved three steps: (1) non-interrupted initial narrative, (2) questioning the points raised in the initial narrative and (3) further questioning areas of interest relevant to the research. The interviews underwent narrative and thematic analysis. The results from the two participants are not indicative of the experience of all people with HI, but it highlights the uniqueness of people facing the same challenge. This supports the concept that care needs to be individually tailored and follow a patient-centred approach. The model in Manchaiah et al. (2011) has been used to develop internet-based pre-fitting counselling tools. However, due to complications with high rates of participant withdrawal and statistically insignificant results between groups, the study could not draw any concrete conclusions about the applicability of the patient journey's use in this setting (Manchaiah, Rönnberg, Andersson & Lunner, 2014).

The patient journey model has not exclusively followed individuals with HI. Manchaiah, Stephens and Lunner (2013) followed communication partners' journey through their experience with their partners HI. They interviewed nine communication partners; starting off with asking them to narrate their journey, following up with more specific questioning based on their reports and including some general questioning asked to all participants. After thematic analysis, 31 sub-themes were reported by most participants. Seven phases were identified; differing from the Ida model, an adaptation phase was added. This study highlighted the similarities and differences between professional and communication partners' perspectives.

Qualitative studies. While no research specifically using a patient journey model to design a qualitative study following CI users, there is a growing culmination of qualitative

studies within the CI user literature. Athalye, Mulla and Archbold (2014) explored the experiences of adults who underwent CI candidacy assessment and did not meet the requirements in the United Kingdom (UK). They interviewed 10 adults that revealed they were upset with the candidacy testing methods and believed they did not represent their difficulties in the real world accurately. The participants also noted that after their candidacy appointment there was a severe lack of support and advice. The conclusions drawn from this information highlighted the social and emotional stress that those with severe-to-profound hearing loss go through and therefore the need to either rework assessment criteria or provide ongoing support for these individuals.

Rembar, Lind, Arnesen and Helvik (2009) conducted a qualitative study that aimed to establish a deeper understanding of how CIs have impacted patients' lives. They used two open ended questions in a written format that was sent to 107 patients of a local CI clinic in Norway. They received 74 completed questionnaires. Two of the questions focused on the positives of CIs and the other two focused on the negatives of CIs. The common themes discovered were that the CI provided a 'new life', helped them interact with the world, and hear the world more easily. The results concluded that there was an overall positive view towards their experience with CIs and that those positive experiences go beyond hearing ability/speech perception. A few other studies have conducted qualitative research using an interview format in the CI field. These studies mainly have focused on patient experiences post-implantation and their views and emotions following implantation (Finlay & Molano-Fisher, 2008; Hallberg & Ringdahl, 2004; Hogan, 1997).

A large multicentre international study in the UK and Australia attempted to address and answer the reasons for low CI uptake in older adults (Bierbaum et al., 2020). The study included 55 postlingually deafened adults over the age of 50 years. Interviews took place individually or in focus groups depending on the participants preference and the interview

questions were supplied in advance. Following thematic analysis, a complex and diverse set of barriers and facilitators were established, with some differences between the two countries. These results could help develop strategies to increase referral numbers and surgeries.

Although there is minimal but growing qualitative evidence addressing adult CI users' experiences, a multitude of studies have assessed subjective experiences using QOL measures. These studies conclude that CI users have increased QOL and improve speech perception results post-implantation (e.g. Cohen et al., 2004; Damen et al., 2007; Klop et al., 2007). Hinderink, Krabbe and Van Den Broek (2000) developed the Nijmegen Cochlear Implant Questionnaire (NCIQ) which allowed for more detailed information to be gained about CI users' QOL and included social and psychological domains. However, what these studies fail to provide is individualised patient experiences and do not allow the patient to go into detail about their story. Questionnaires limit the amount of complex personal material that could be helpful in developing better patient-centred care. This indicates the need for more qualitative research; more specifically, qualitative research using patient journey models.

New Zealand Context

Limited funding and waiting list. NZ has very limited public funding for adult CIs. Due to this, the waiting lists are long and the criteria is strict. Those who are on the waiting list are ranked in a priority order, with preference for those who are working. Many people who could benefit from a CI are unlikely to receive one unless they privately fund. In 2010 there were 92 people on the waiting list in NZ and funding allowed for 20 per annum, with mean times on the waiting list approximately four years (Gunn, 2010). Bird (2013) discussed the waiting list during this year. The government had approved more funding (50% increase) which allowed for up to 60 adult implantations per year and 142 adults were on the waiting list. However, J. Mustard (personal communication, May 20, 2020) reported that only 40

adult implantations are currently funded publicly per annum in NZ. She mentioned because of the low numbers of publicly funded implantations there has been an increase in people proceeding privately. The article noted that including charitable donations and public funding, the longest time spent on the waiting list was approximately two years, which was a significant decrease from previous years. There are no current articles discussing the waiting list in NZ. However, the MoH states there is more than $8 million in funding for CIs (Ministry of Health, 2015). As mentioned earlier the approximate cost of CI surgery, device and follow up is $50,000NZD. This budget would allow for 160 implantations per annum; this number includes children who are prioritised. Time spent on medical waiting lists has been shown to be detrimental to patients by increasing stress levels and lowering overall quality of life (Mahon et al., 2002). Guitar, Giles, Raymond and Welch (2013) sent health and stress related questionnaires to CI users (n=119) and those on the CI waiting list (n=44). After data was analysed using Analysis of Covariance (ANOVA) and adjusting for potential confounding variables, the results showed the waiting list group had higher levels of stress and illness. Of that group, those who had spent more time on the waiting list reported more persistent health issues and higher use of medications. They concluded that the waiting list likely increased stress levels and affected the participants physical and mental health.

Absence of local research. Lack of funding causing long waiting times is not the only issue in NZ. There is an absence of recent research documenting the subjective experience of CIs for postlingually deaf adults living in NZ. The researcher was unable to find any published studies that documented this qualitatively. As mentioned previously, QOL studies are a common way to assess subjective benefits of CIs. Looi, Mackenzie and Bird (2011) used a questionnaire that included 60 items from the NCIQ and 11 derived from the Cochlear Implant Satisfaction Questionnaire to analyse 94 postlingually deafened adult CI recipients and 70 postlingually deafened adults on the CI waiting list. The results indicated

that the CI recipient group scored significantly better than the waiting list group. After analysing the two groups' questionnaire data using independent samples t-tests and a two-way repeated-measures ANOVA, it showed a significant difference between the two groups in all six subdomains. The conclusions drawn were that the CI recipient group had an overall higher QOL and satisfaction rating when compared to the waiting list group and acknowledges the difficulties faced for those on the waiting list with substantial HI.

Study Rationale and Aims

As highlighted in section 1.7, there is extremely limited research using patient journey models to qualitatively assess CI user experiences. The focus has mainly been on the experience of HI and their journey of aural rehabilitation with the assistance of HAs. This study will provide information to assist in addressing this gap in knowledge.

As mentioned above in section 1.8, NZ is lacking research in the subjective experiences for CI users and there is no qualitative research addressing this. Each country has unique systems. Therefore, research globally might not be indicative of the individuals' experience in NZ. It is important to acknowledge the gap in research and gain local information on what New Zealanders with CIs experience. This study aimed to help fill this gap in local research.

There are no studies that have addressed the experience of individuals that privately funded their CI and if they have similar outcomes to publicly funded CI users. Therefore, this study aims to assist in evaluating those outcomes.

The aims of this study are to:

- Develop a better understanding of a HI adults' journey from having HAs to getting a privately funded CI. This information will assist clinicians in providing a better level of care by understanding the common patient journey.

- Determine the sources of funding to help with suggestions for alternative funding methods.
- Help answer if individuals who privately funded their CI have similar outcomes to those who have them publicly funded. This could provide evidence to encourage an increase in public funding in NZ.

In summary this chapter has introduced: HI and its effects on the individual, the benefits and limitation of HAs, CI overview, the process of receiving a CI in NZ, the patient journey models, the NZ context, study rationale and aims. The following chapter will provide a detailed methodology used in this study.

Method

Ethics and Māori Consultation

This project was approved by the University of Canterbury Educational Research Human Ethics Committee on the 28th of March, 2019 (Appendix A) and included the amendments to the application made on the 21st of March, 2019. Another amendment was approved on the 8th of April, 2019 (Appendix B). The Ngāi Tahu Research Centre acknowledged and supported the research proposed (Appendix C).

Research Design

Qualitative framework. There are two main ways of collecting and interpreting data: quantitative and qualitative. Quantitative data is information about quantities which is represented numerically and assumes a fixed and measurable reality (Minichiello, Aroni & Minichiello, 1990). Qualitative data is descriptive and reports on phenomenon that are observed not measured; the data is represent non-numerically. This means qualitative research is appropriate to help understand people's beliefs, attitudes, experiences, behaviours and interactions. This style of researching and data collection was developed within psychological studies to assist with evaluating human behaviour (Pathak, Jena & Kalra, 2013). Qualitative research is important as it allows for information to be gathered that cannot be obtained through the measurement of variables alone (Gibson, Timlin, Curran & Wattis, 2004). Qualitative research is often conducted in three ways: (1) observational, (2) interviews and (3) documentary/textual analysis of written records (Pope & Mays, 2006). When qualitative and quantitative research is combined, there can be a much greater understanding of all aspects in that field and is particularly helpful when researching health issues. This study was constructed around a qualitative framework that follows the journey model. The advantage to using the qualitative structure in this study is the results are more likely to show the common experience without disregarding the individual journey.

Retrospective approach. Originally the current study intended to follow a small group of individuals through their rehabilitation journey with several interviews over each of the stages. However, due to time constraints and low private CI uptake in NZ, it was not feasible to follow through with that design. The choice to move to a retrospective framework allowed for the same questions to be asked but all at the end of the rehabilitation process. Although this leads to some limitations, it ultimately was the best decision for the study to go ahead due to the time constraints of a Master's thesis.

Consent and information forms for participants. Information sheets and consent forms were developed and sent through to the CI Clinic for distribution via mail to clients in their database that were within the inclusion criteria (Appendix D & E). The information sheet covered the purpose of the study and what would be required from the participants if they wished to participate. Before distribution, the CI Clinic requested some minor adjustments to the information sheet to fit within their standards of research. The consent forms were either returned via mail or scanned and returned via email.

Before each interview started recording, verbal consent was obtained along with a short breakdown of what was to be expected and encouragement for the participant to give as much detail as possible in their answers (Appendix F)

Interview structure. The interview was structured on the life adjustment journey model introduced in the literature review. The interview was designed to allow for broad answers with follow up points/questions for refinement of those answers. The design of the interview questions was semi-structured to allow for the individuals variance and uniqueness while still obtaining crucial points within the journey (Appendix G)

Participants

Inclusion criteria. This study aimed to interview people who recently transitioned from HA to a privately funded CI within NZ. The researcher decided to include CI users that were between 6 and 24 months post-switch on. The rationale was due to the commonly reported poorer performance and emotional distress within the early months post switch on which could affect the outcome of the results. There is evidence that most CI user's speech recognition plateau from 6 to 12 months, with almost all plateauing by 18 months (Holden et al., 2013). The proposed range was originally 6 to 18 months but was expanded to 24 months to increase the potential participant pool. The upper limit of this range was to try and mitigate issues with recalling their experience.

Participants had to be over 18 years of age and have sufficient verbal English in order to undergo the interview format smoothly. Only participants with no cognitive impairments, not diagnosed with a syndrome and no major physical impairments were included, once again for the ability for the interview process to be as simple as possible, and for recollection of events to be accurate.

Researchers decided that only those who had never been implanted with a CI before would be included. That is, participants could not be undergoing, reimplantation or bilateral implantations. Because the study focused on the experience of transitioning to a CI, it needed to be the individual's first CI to help answer the research questions. One of the aims of the study was to examine the funding methods for individuals that could not access public funding, so only those who had funded their CI privately were included.

Recruitment. Two CI programmes were contacted within NZ and given an overview of the study. Both were interested in helping with the recruitment process. The participant pool was large enough to just use one programmes database of individuals. After some minor

adjustments to the participant information sheets, the CI Clinic distributed the information sheet and consent forms to the individuals in their database that met the inclusion criteria. Consent forms were returned via mail or email. The participants were then contacted via email to organise a mutual time and place for their interviews.

Participant privacy. All participants were assigned a number and information said in the interviews that could be considered identifiable were excluded from the results. Terms such as the "CI Clinic" were used to help protect participant identity.

Data Collection and Analysis

Interviews. Twelve participants took part in a semi-structured recorded interview (~one hour) that covered the key elements of the life adjustment model to represent the participants' journey from HA to CI. The interview structure was followed, but not necessarily in order. The participants were encouraged to freely speak about their experience so follow up questions were often personalised and/or out of order to keep the flow of conversation more natural. The interview was recorded using an Olympus DS-500 digital voice recorder. Interviews took place either at the University of Canterbury or at the participant's home if they did not live in the local region. The researcher travelled around NZ for the interviews as this took pressure off the participants and allowed for more flexibility for availability. The participants were given $40NZD to thank them for their time. If they were required to travel, they were given an additional $20NZD.

Interview transcription. Audio files were uploaded to Rev.com and transcribed professionally. After external transcription, the researcher manually edited any mistakes and added to areas labelled 'inaudible' where possible.

Questionnaires. Three surveys were distributed. The 12 participants could either complete them online using Qualtrics or fill out a hard copy and return to the researcher via post. Hard copies were posted with return postage included when the participants elected to

complete them via post. Collectively, all three surveys would take approximately 30 to 45 minutes to complete. The three surveys used were: Assessment of Quality of Life, specifically the AQoL-6D (Maxwell, Özmen, Iezzi, & Richardson, 2016), NCIQ (Hinderink et al., 2000) and general demographic questions that were designed by the researchers (Appendix H, I & J). The CI Clinic was sent a form to complete which included: objective testing results, CI model, surgical outcome, HA models and HA use (Appendix K).

Participant quantity and saturation. Before data collection, it was established that ideally that 10 or more participants would be suitable. This was based on the nature of the qualitative work and participant numbers commonly seen in similar studies. Research determining adequate sample sizes for phenomenological qualitative studies have ranged from Creswell (1998) recommending between 5-25 and Morse (1994) recommending at least six. However, it was acknowledged that reaching saturation was more important than reaching a set number of participants.

Saturation has been commonly determined as the point in coding when no new codes occur in the data or the point at which additional data does not emerge any new themes (Saunders et al., 2018). The researcher determined saturation using this principle, but only for main themes. Ideally, the subthemes would also reach saturation, but due to the area of research it was to be expected to see a lot of variation within the subthemes. It would require a much larger sample size to reach saturation within the subthemes and it is unsure if saturation of subthemes would provide more assistance with answering the research questions.

Thematic analysis and coding. The researcher read through each of the transcripts several times to become familiar with each participant's story and made brief notes on each. This was followed by a manual process of identifying the main themes and filling them into a

table in Excel, using the interview questions as a template. The initial theme analysis was shown to both primary and secondary supervisors and discussed to improve reliability.

After the raw themes were found, the researcher completed a more detailed and scrutinous process of coding the themes and subthemes by importing the transcripts into Nvivo 12. Using this software, the researcher began coding the themes and subthemes and assigning them in appropriate node groupings within each stage of the journey. Main themes that did not exceed at least eight out of twelve participants were not included in the results. Themes that were very similar were combined into a single overarching theme.

For each stage in the journey a mind map was created using Nvivo 12 to display results along with a table of results (e.g. Figure 2 and Table 5). The tables were made showing all themes and corresponding subthemes along with one supporting quote for each subtheme. The quote that best highlighted each subtheme had priority. However, there was a conscious effort from the researcher to try and evenly distribute the quote use over all the participants where applicable.

A summary list of all the themes and subthemes were sent via email to all the participants with a request for them to respond with their thoughts on if their personal experience is acknowledged within the analysed data. This process was used to validate the results and add any final thoughts the participants wanted to share.

Quantitative data. The data collected from the surveys was used to correlate with the interview data and to help with answering the research questions. However, there were no statistical analyses conducted on this data. Basic descriptive statistics were performed using Qualtrics figures and tables were made using Excel.

Results

In this chapter the results are presented in a series of thematic maps and tables. The journey was broken down into four sections based on the life adjustment model; ‘Before Rehabilitation’, ‘During Rehabilitation’, ‘After Rehabilitation’ and ‘Throughout Journey’. There are five thematic maps; an overview of the main themes for the patient journey (figure 2) and subsequent breakdown of each stage in the journey and its corresponding main themes and sub-themes (figures 3-6). The first two tables below show group demographic and audiological information (tables 1 & 2). Questionnaire data for each participant, along with mean data is displayed below (tables 3 & 4) and subsequent tables supply supporting quotes from the participants for each subtheme and display how many participants mentioned each of the main themes and sub-themes (tables 5-8).

There were seven main themes identified in the Before Rehabilitation stage (See Figure 2, Figure 3 and Table 5). For each main theme, between 4 and 11 sub-themes were identified. Seven main themes were identified in the During Rehabilitation stage (See Figure 2, Figure 4 and Table 6). For each main theme between 1 and 7 sub-themes were identified. Eight main themes were identified in the After Rehabilitation stage (See Figure 2, Figure 5 and Table 7). For each main theme between 2 and 12 sub-themes were identified. Three main themes were identified Throughout Journey (See Figure 5 and Table 8). For each main theme between 5 and 9 sub-themes were identified.

Participant Information

Table 1. Overview of Participant Demographics

Characteristics	Participants (n = 12)
Gender	
Male	67%
Female	33%
Age (mean ± SD)	69 ± 10 years
Marital Status	
Married	75%
Single	8%
Widowed	8%
De facto Partnership	8%
Employment Status	
Retired	83%
Full Time Working	17%
Ethnicity	
NZ European	100%
Average Travel Time Via Car to Nearest Clinic (hours)	3.4
Range	0.25-7.5

Table 1 reveals that majority of the participants were male and one third of the participants were female. The data also shows that majority of the participants were older, with ten out of twelve being retired. The majority of participants were married. All participants identified as New Zealand European. The average travel time for participants was 3.4 hours, this was calculated using Google Maps as an estimation.

Table 2. Overview of Participant Audiological Information

Characteristics	Participants (n =12)
Age of HI onset (mean ± SD)	30 ± 18 years
Range	2-60 years
Cause of HI	
Unknown	33%
Noise Induced	25%
Rubella	17%
Otosclerosis	8%
Ototoxic Medication	8%
Meniere's	8%
Device Arrangement	
Bimodal	58%
Unilateral CI Only	25%
Bilateral CI	8%
CI + CROS	8%
CI Brand	
Advanced Bionics	50%
Cochlear	33%
Oticon Medical	8%
MED-EL	8%
Approximate Time Since Surgery	
2 years	33%
1.5 years	33%
1 year	17%
>1 year	17%

Note. Approximate date after surgery was displayed to the nearest half year and calculated between surgical date and date of the interview. Participant 111's age of HI onset at two years of age was mild-moderate and hearing level deteriorated in adulthood. Participant 109 had both CI's implanted at same time; one was privately funded.

The data displayed in Table 2 show there is a broad range in what age participants first experienced HI, the youngest at two years old and the oldest at 60. There was variability amongst the causes of hearing loss with the most prominent being unknown. The most popular device arrangement was a bimodal fitting with a single CI fitting being the next most prominent. Advanced Bionics made up half of the brand choice followed by Cochlear for one third of the participants. There was a mostly even divide between participants that were fitted between one and two years.

Questionnaires

Table 3. Nijmegen Cochlear Implant Questionnaire scores for each domain

		Physical		**Psychological**		**Social**
PART NO.	BASIC SOUND PERCEPTION	ADVANCED SOUND PERCEPTION	SPEECH PRODUCTION	SELF-ESTEEM	ACTIVITY LIMITATIONS	SOCIAL INTERACTIONS
100	62.5	50	75	45	61.1	48
101	80	65	92.5	67.5	70	77.8
102	77.5	75	50	47.5	70	62.5
103	67.5	60	81.3	75	77.8	66.1
104	60	50	82.5	72.5	72.2	70
105	75	52.5	82.5	52.8	72.5	72.5
106	80	62.5	90	55.6	77.8	82.3
107	70	55.5	60	55	57.5	60
108	50	32.5	100	55.6	59.5	73.9
109	42.5	25	70	10	7.5	32.5
110	60	50	72.5	75	83.3	70
111	47.5	50	95	65	40	35
MEAN	64.4	52.3	79.2	56.4	62.4	62.6
SD	12.9	13.5	14.7	17.9	20.8	16.1
SEM	1.6	1.9	1.7	2.4	2.6	2
RANGE	42.5-80.0	25.0-75.0	50.0-100	10.0-75.0	7.5-83.3	32.5-82.3

The data displayed in Table 3 shows the domain with the highest mean score (scores range from 0-100) is speech production and the domain with the lowest mean score is advanced sound perception. The domain with the largest individual variability is activity limitations with a range from 7.5-83.3.

Table 4. AQoL-6D unweighted scores for each domain and total score

PART NO.	INDEPENDENT LIVING	RELATIONSHIPS	MENTAL HEALTH	COPING	PAIN	SENSES	TOTAL SCORE
100	21	11	16	11	10	11	80
101	22	11	18	12	11	12	86
102	21	12	10	9	13	13	78
103	16	11	19	13	11	12	82
104	21	13	19	13	12	13	91
105	20	12	19	13	11	11	86
106	22	12	18	14	12	14	92
107	22	13	19	13	13	14	94
108	22	12	17	12	13	13	89
109	20	10	9	9	9	10	67
110	19	10	17	12	11	14	83
111	22	13	20	14	8	13	90
MEAN	20.7	11.7	16.8	12.1	11.2	12.5	84.8
SD	1.8	1.1	3.6	1.7	1.6	1.3	7.5
RANGE	16-22	10-13	9-20	9-14	8-13	10-14	67-91

The data displayed in Table 4 shows raw additive scores for each participant in each sub domain. The largest variability in scores is observed in the mental health domain, with a range scoring from 9-20. Most participants scored in the higher bracket within each domain also reflective in their total score (max score =100).

Overview of the Patient Journey

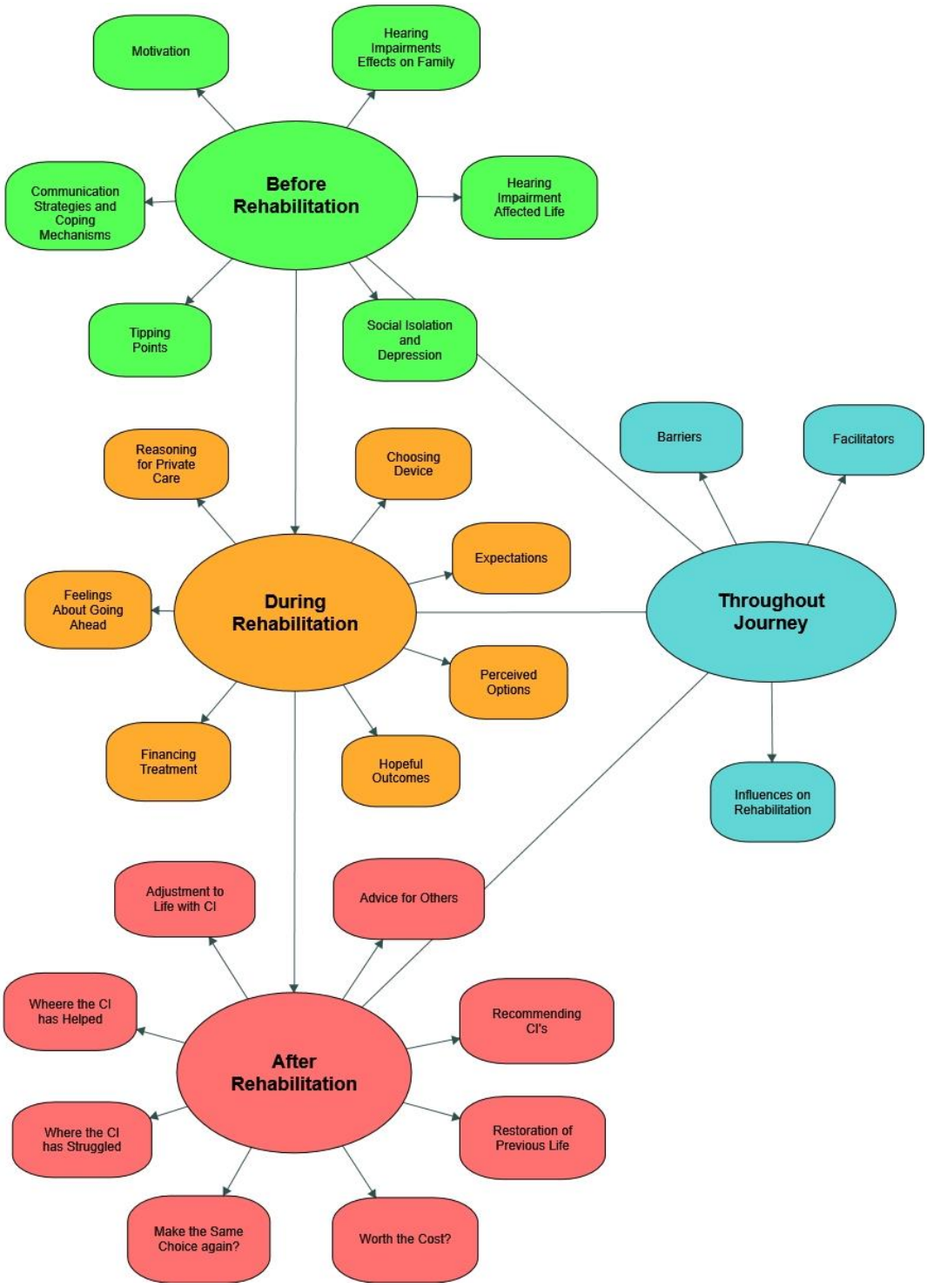


Figure 2- Thematic map of the Journey Model, an overview of the main themes

Before Rehabilitation

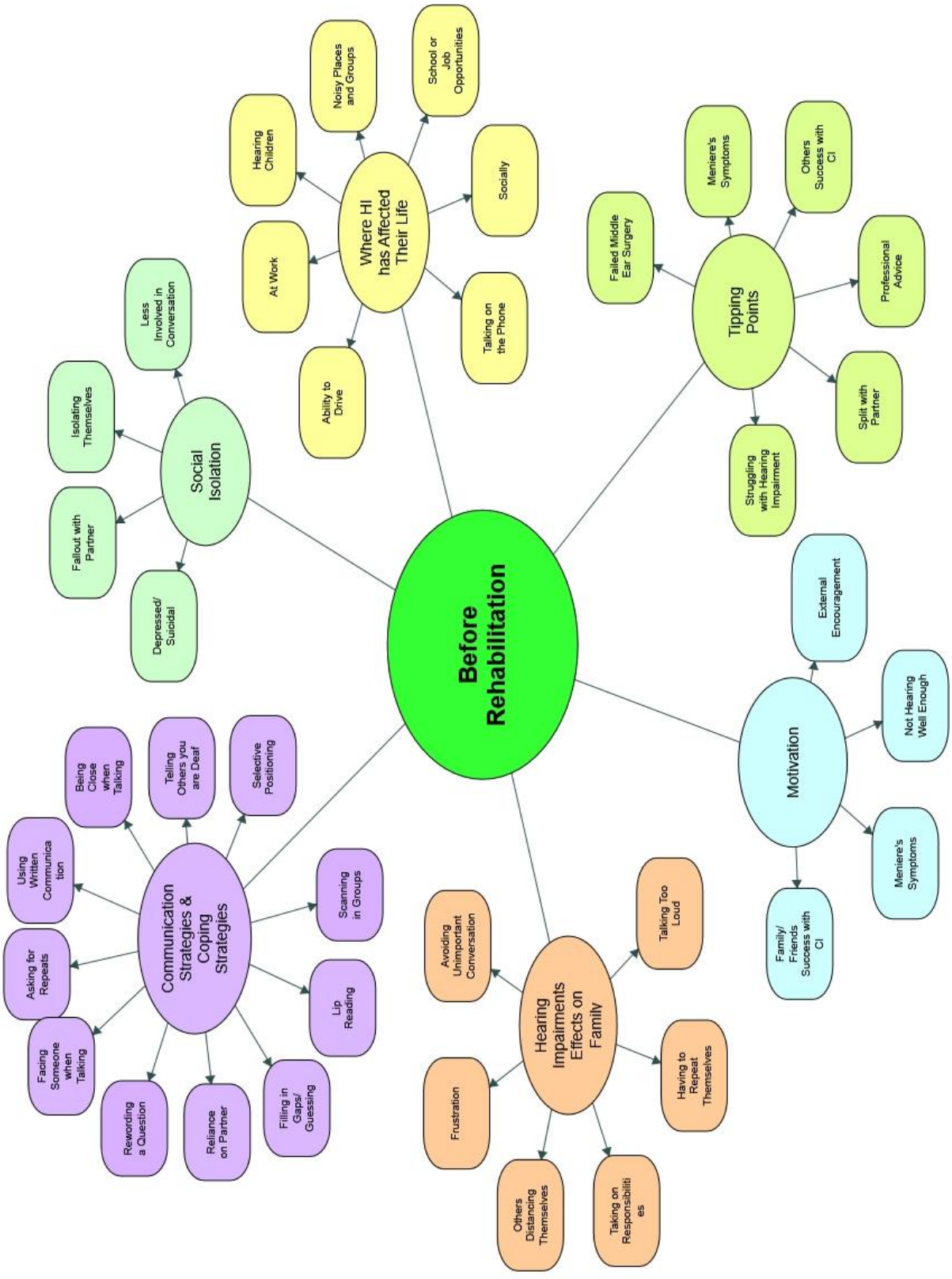


Figure 3– Thematic map of themes and sub-themes before rehabilitation

Table 5. Before Rehabilitation themes and sub-themes with corresponding supporting participant quotes. Themes and sub-themes are organised from mentioned most often to least often. Numbers in italitcs under themes display how many participants that mentioned those themes.

Themes	Sub-Themes	Supporting Quotes
Motivation *12*	Not Hearing Well Enough *7*	**P101** "Well, every year I would go back and have my hearing aid re-tuned and my hearing got worse every year. It was noticeably worse 12 months after the last tuning so I was quite motivated to go back and get it improved…"
	External Encouragement *5*	**P110** " I spoke to a chap in [my home town] in the audiology department and he was very knowledgeable and helpful. He started me on the path."
	Family/Friends Success with CI *2*	**P105** "Oh, watching the brother and sister basically. If it hadn't been for them, I wouldn't even know about them really… yeah, the difference was amazing. If it could work for her, maybe it could work for me."
	Meniere's Symptoms *1*	**P102** "I was like I was desperate, I was not in a good place. I thought I had no other option what to do with myself because the tinnitus was so bad at night and I was not functioning well at work at all. Sometimes, I would feel like I would have to go and vomit in the toilet, or whatever."
Tipping Points *12*	Struggling with Hearing Impairment *8*	**P107** "Didn't have a clue what they're talking about, no matter how loud my volume was on my hearing aid, it just got worse and worse. I thought, well, now's the time. Now's the time to do it."
	Professional Advice *3*	**P108** *Referring to conversation with audiologist* "I was getting frustrated with the ReSound hearing aids. They weren't strong enough and it was he that suggested that perhaps I could look at cochlear implant."
	Others Success with CI's *2*	**P111** "I was at a friend's birthday party and a woman had a cochlear implant there to start that candle in me…That was really the defining point of me actually doing something about it."

	Failed Middle Ear Surgery *1*	**P100** *Referring to the failed stapedectomy* "Definitely, I was nearly stone deaf because he (ENT) said that was the only step left. He thought after going through the process that it would just be the next step…"
	Meniere's Symptoms *1*	**P102** "When I did it I wasn't very well, because with the Meniere's I had off-balance, vertigo, a lot of issues with my... just generally not feeling very well in the head sometimes."
	Split with Partner *1*	**P109's Wife** "Well we actually split up last year because of that, because he couldn't hear. So I think it was, that was one of the deciding factors I think, for him having the op." **P109** "That was a factor. I got told that the Cochlear implants was the last that, once you got that far that's as far as you could go."
Communication Strategies and Coping Mechanisms *11*	Lip Reading *7*	**P107** "I've quite got good at lip reading…"
	Asking for Repeats *5*	**P102** "Probably I'd just ask people to say something again. I try to be quite normal about it without making people think, she's not understanding what I'm saying."
	Filling in Gaps/Guessing *4*	**P110** "…You start saying, "Yes." when you haven't heard the question. And it's stupid. It's absolutely stupid."
	Reliance on Partner *4*	**P100** "…I struggled to understand speech. So, when I went to pay something I had to take her to the shop."
	Facing Someone when Talking *3*	**P111** "…all my friends have known for years that I've been deaf. So they've been pretty good at talking to me and looking at me…"
	Telling Others You are Deaf *3*	**P103** "I always tell them, or told them, that I don't hear very well. So as long as you speak slowly and clearly to me, I'll hear most of it."
	Selective Positioning *2*	**P103** "I try and position myself where I can hear most people. A round table is better than a long table."
	Using Written Communication *2*	**P100** " If someone asked me a question, she would be there with a pen and paper, write the

		question down so I can read it and then answer.”
	Being Close when Talking *1*	**P110** “…Standing close to people…”
	Rewording a Question *1*	**P101** “I would often stay quiet about it, but ask the question another way, or I would do some research, it is amazing how much you can infer.”
	Scanning in Groups *1*	**P102** “…I just tend to just lock to one person and then to the other. You're moving your head all the time because you're looking at what that person's saying to that person…”
Where Hearing Impairment Has Affected Their Life *11*	Socially *9*	**P103** “…I don't hear jokes. At the end of a sentence, nearly everybody's voice goes down and I miss that. And you can't repeat a joke, can you?”
	At Work *7*	**P110** “…I retired at 60, not 65, because I was very concerned about my job. If you can't hear, you're useless. You know?...”
	Talking on the Phone *4*	**P104** “ I didn't like answering the phone… because some people were very hard to hear. And the phone especially, if you get foreigners, just about impossible.”
	Noisy Places and Groups *4*	**P105** “ I'd get more frustrated every day. I'd sort of get the bulk of it. I couldn't hear raffle numbers and couldn't hear speeches and couldn't hear anything. When I knew it could be so much better…”
	School or Work Opportunities *3*	**P102** “…I got a lot of applications for jobs that were declined because I thought, "Right, okay. As soon as they saw me in the interview, no one is going to want that sort of person." That's a bit of a problem.”
	Hearing Children *2*	**P109** “Yeah. I couldn't understand them at all. Even a seven year old, I couldn't understand her.”

	Ability to Drive *1*	**P100's Wife** "…he wasn't allowed to drive, he couldn't go out anywhere without me accompanying him."
Hearing Impairment's Effects on Family *10*	Frustration *6*	**P107** "Very frustrating, very much so. You sort of overcome that by saying oh well, you sit and shut up, and don't say anything."
	Having to Repeat Themselves *4*	**P107** " Of course it effects them, because I get tired of repeating it, and I keep repeating it."
	Others Distancing Themselves *3*	**P109** "Some people would avoid talking to you before the implant. You could pick it."
	Taking on Responsibilities *2*	**P103** "When the twins were babies, if they cried during the night, I wouldn't hear them. My husband would hear them and he'd be up and change them and feed them before I even knew he was up."
	Avoiding Unimportant Conversation *1*	**P104's Wife** "And I did get to, maybe only talk about important things, that was all the... we didn't do the frivolous chat because it was too hard to get the message across, and you think, is it worth it?"
	Talking too Loud *1*	**P103** "…my daughter, sometimes said, oh, Mum. You're talking too loud."
Social Isolation *10*	Less Involved in Conversation *10*	**P104** "I probably reasonably reluctant to talk to people because some people were very hard to hear. And the phone especially, if you get foreigners, just about impossible."
	Isolating Themselves *5*	**P110** "I knew that I was going to end up probably spending all day in my workshop there not wanting to mix with people. I was a social sort of person. I like talking to people."
	Depressed and or Suicidal *2*	**P102** *Referring to tinnitus* "I was pretty bad. In fact I thought I was suicidal… Hope wasn't in my life at that time. I thought I really struggled with the lack of sleep…"
	Fallout with Partner *1*	**P109** "We split up prior to the operation as well, two months there. I just gave up and said, no, I need to be by myself. I'd rather be by

		myself and I pretty much moved out of here, went and stayed in a shed for three months.”

The data displayed in Table 5 show the participants experiences via themes and sub-themes before their rehabilitation with a CI. For many participants, where HI affected their life, the most common was their ability to be socially involved. Some would struggle in social environments and would avoid them altogether due to their HI. Although majority of the participants were retired, upon reflection, HI had a significant impact on their time at work. For some it was the reason they retired early and for a few it limited their school and work opportunities.

HI not only affected themselves but those around them. Half of the participants revealed frustration being a common feeling that their loved ones experienced with them due to their HI and one quarter mentioned their family having to repeat themselves often. A few witnessed family and friends distancing themselves due to their HI and it was evident from the interviews that this had a significant impact on the social involvement of those individuals.

The impacts of HI led most participants into a feeling of social isolation and/or depression. Most revealed they were less involved in conversation which also lessened their enthusiasm for attending social events/activities. Almost half the participants would socially isolate as they found themselves better off alone. Naturally, coping mechanisms and strategies are developed to compensate for the difficulties associated with having a HI. The most common strategy was lip reading, followed by a reliance on a partner. There was a wide variety in how the participants developed strategies and coped with the 11 different sub-themes identified.

Due to HI impacting not just themselves, but their friends and family, a major factor in some participants motivation was external encouragement. This came from multiple sources; family, friends and hearing professionals. However, for most the major motivation was simply not hearing well enough and the drive to change this. In combination with motivation, a tipping point was crucial in many participants journey forward. Their most common tipping point was struggling with their HI, as for many their hearing was deteriorating and their HAs were unable to perform adequately for their needs. For some, professional advice was the prominent factor in pursuing with treatment in the form of a CI. In summary, all participants struggled with their HI and found various ways of coping, but that was not sufficient. This led some to social isolation and/or depression, but also instilled motivation towards a CI rehabilitative path.

During Rehabilitation

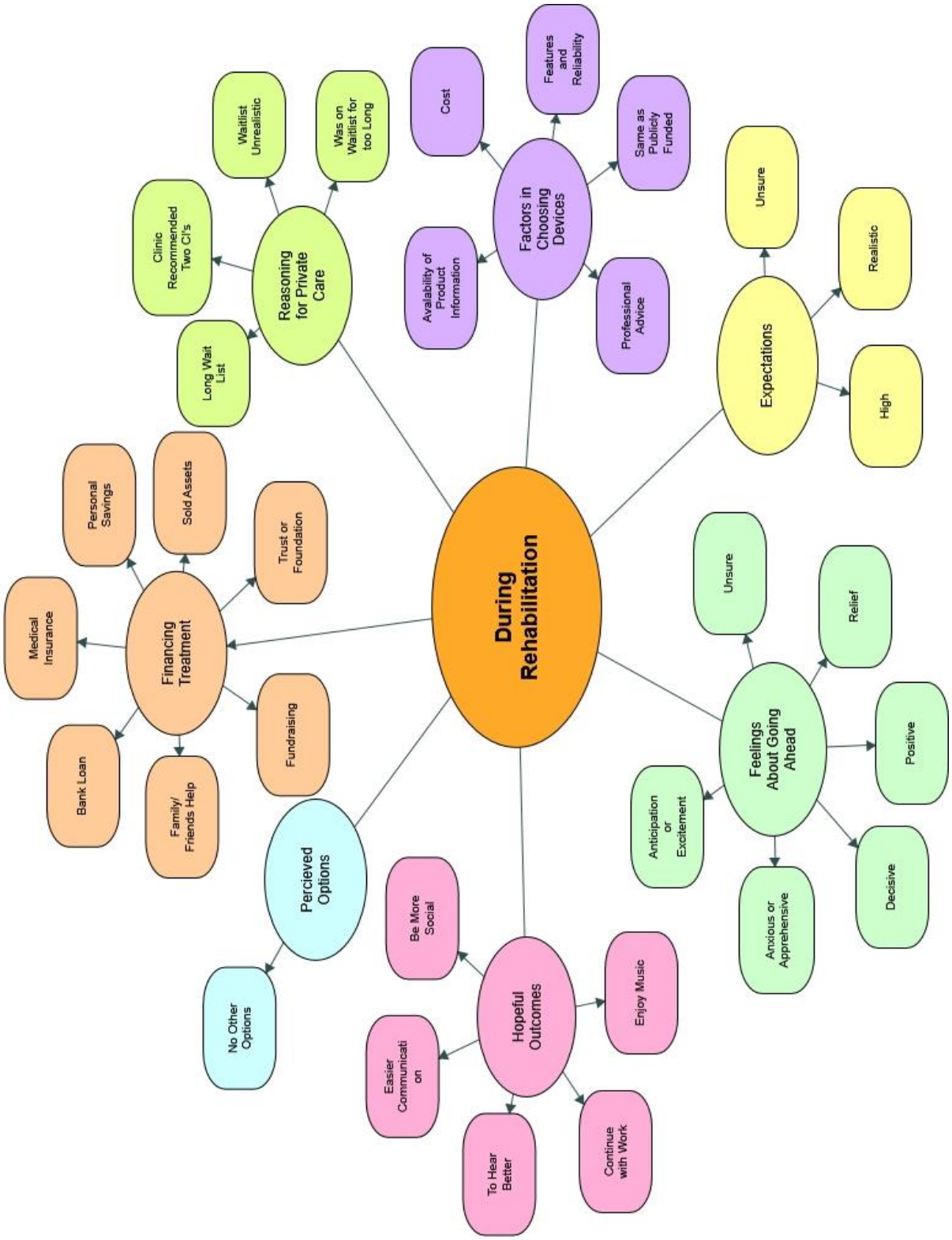


Figure 4- Thematic map of themes and sub-themes during rehabilitation

Table 6. During Rehabilitation themes and sub-themes with corresponding supporting participant quotes. Themes and sub-themes are organised from mentioned most often to least often. Numbers in italitcs under themes display how many participants that mentioned those themes.

Themes	Sub-Themes	Supporting Quotes
Expectations *12*	High *5*	**P105** "Oh I'd put them on straight away and hear perfectly."
	Realistic *5*	**P101** "…[The CI clinic's] paid program is pretty full on in terms of their number of assessment and orientation type meetings beforehand to make sure that your expectations are realistic, and aligned, and having 2 of their staff you are talking to, so it is not theory, I think in terms of what happened and my expectation, they were aligned."
	Unsure *2*	**P102** "Unsure. I wasn't sure what would pan out. I had in my mind that, that wouldn't be good. But, I thought, "Give it a go." You had to be hopeful; that's my feeling that I had before I went…"
Factors in Choosing Devices *12*	Features and Reliability *5*	**P104** "I chose the Cochlear implant mainly because it was compatible with the iPhone I have. It was also medium priced and I was told that it was a reliable brand."
	Professional Advice *5*	**P103** "I have an advanced bionics implant; my audiologist chose this model because of my level of hearing and it has proved to be very successful"
	Cost *3*	**P101** "My consultant with the ENT stated that from a performance point of view they were all comparable. So, it came down mainly to cost. Since I was funding my own, I chose the AB as it was significantly cheaper."
	Availability of Product Information *2*	**P102** "I looked through all the booklets and pamphlets on the models that were available. I looked at, what were the benefits of it? Their chart that Oticon had brought out, the speech recognition and exactly what is going to happen, I thought, "No, this is what I want," and that's why I chose Oticon."

	Same as Publicly Funded *1*	**P109** "The public funded one was the one that they wanted to use. So, I thought, well, no point in getting two different brands."
Financing Treatment *12*	Personal Savings *7*	**P108** "Yeah. And we had a little bit of money put aside so we decided to use that."
	Medical Insurance *4*	**P106** "…I did get, as you're aware, there's no funding for the implant. We just have Southern Cross insurance. They paid 80% of the actual cost of the surgery."
	Family/Friends Help *2*	**P103** "…Unfortunately, in a way, my brother died a few years back and he gave the twins so much money each. And they very kind, between them, funded my implant."
	Trust or Foundation *2*	**P102** "…First of all, I went on Givealittle, but then somebody said to me, "How about you try the _____ Foundation," which they've got funding in my company with stuff. I applied for that for the full amount that was quoted by [the CI clinic] and they funded it in total…"
	Bank Loan *1*	**P109's Wife** "Yeah. We just put it on our mortgage because it was up for renewal anyway." **P109** "I've got a mortgage, so..."
	Fundraising *1*	**P108** "We did some fundraising…Down at my arts and craft club."
	Sold Assets *1*	**P110** "So, I gave it a lot of thought, and I thought, well, what's the most important thing in my life? And it wasn't vehicles. It was hearing. It was being able to communicate with people."
Reasoning for Private Care *12*	Wait List Unrealistic *8*	**P101** " I mean it is an option that is there to make people feel as though they are not desperate, but it is not actually a realistic option."
	Long Wait List *3*	**P100** "Yeah that's right, we went privately. I didn't think I could stand two years in isolation."

	Clinic Recommended Two CI's *1*	**P109** " [The CI clinic] said… the second one was the bee's knees and just improved it big time."
	Was on Waitlist for Too Long *1*	**P105** "Oh two and half, three years. I got in touch and said what's the story? Am I moving up the list? What's happening? And they said, "No, you're not moving up your list. You're staying very stagnant in the middle of the list." It's not bloody good. I wished they'd told me that in the first place. If they'd told me I wouldn't have wasted two and a half years."
Feelings about Going Ahead *11*	Positive *6*	**P105** "Very positive. Very looking forward to it, yeah."
	Anxious or Apprehensive *5*	**P106** "Once I made a decision, like any medical person, you start looking at the complication rate and start sweating about whether you are going to be one of the 1% who has a complication…"
	Anticipation or Excitement *4*	**P111** " I was really excited about it and thought, gosh, you know, this could be the answer to all my problems"
	Relief *2*	**P101** " Well, I do not know if I felt particularly much, it was, a relief that I could have it done."
	Decisive *1*	**P104** "Well, went, had the appointment and after they had assessed it and sent us the information, that it was just about impossible to get it on public health, we talked it over and we said, yeah, we'll go for it, and as soon as possible."
	Unsure *1*	**P104** "…I really didn't know much about it. I suppose I heard the odd comment, people say, "Oh, yeah, it's a great idea," but I didn't really know. I didn't know how it worked or what the story was."
Hopeful Outcomes *11*	To Hear Better *8*	**P103** "Oh. Well, I had hoped that it would give me a little bit more hearing than what the hearing aid did."
	Be More Social	

	4	**P105** "Just so I could hear again. So, I could hear noise, or I could hear raffle numbers and speeches and then sort of get myself involved a bit more. Sort of before I really got them, I didn't say a lot, but I'd go to places and do things but wouldn't say a lot…"
	Easier Communication *3*	**P107** "Better way of life, I suppose. Hearing a lot better and trying to be in the conversations. Stop asking people to repeat themselves..."
	Enjoy Music *2*	**P106** "…I was interested to see what it did for music."
	Continue with Work *1*	**P101** "Well I wanted to be able to continue in the current state that I was working, I wanted to be able to continue to do the normal things that I needed to do at work in terms of relating to people, leading meetings, participating in meetings, talking on the phone all the things..."
Perceived Options *11*	No Other Options *11*	**P100** "We didn't think there was any other options."

The data displayed in Table 6 show the participants' experiences via themes and sub-themes during their rehabilitation with a CI. After the tipping point, participants evaluate their options. For all participants they did not believe there were any other options, they did not want to persist with the poor performance from their HAs and the CI was the only step forward. After candidacy evaluation the CI Clinic discussed the public and private options.

For almost all participants, the waiting list was unrealistic either due to the strict eligibility criteria or the advice from the CI Clinic team. For those that considered the waiting list an option, it was too long, hence their decision to seek private treatment. With the decision to go private, many found it difficult to decide how to fund the CI. More than half used their personal savings to fund the CI, but for many it was a combination of different funding sources including medical insurance and family support. Cost was a factor for a few

participants in device choice due to funding difficulties. However, most participants decided on which device because it had the best features and reliability, or they trusted professional advice.

With funding organised and device chosen, majority of participants felt positive about going ahead. Several acknowledged they were anxious or apprehensive, predominantly about the surgery or that it will not work for them. With positive feelings comes the prospect of hopeful outcomes. These hopeful outcomes are likely driven by the participants' motivations. The primary hope for after CI implantation was to hear better. For one third the hope was to be more social and involved in conversation. The high costs, positive feelings and pondering hopeful outcomes caused many to have high expectations. An equal amount said their expectations were realistic and this was predominantly mediated by their self-research and professional guidance. None of the participants had low expectations, with only two being unsure. Overall the participants showed a lot of positivity towards cochlear implantation, for all it was the only perceived way forward for them to achieve their hearing goals.

After Rehabilitation

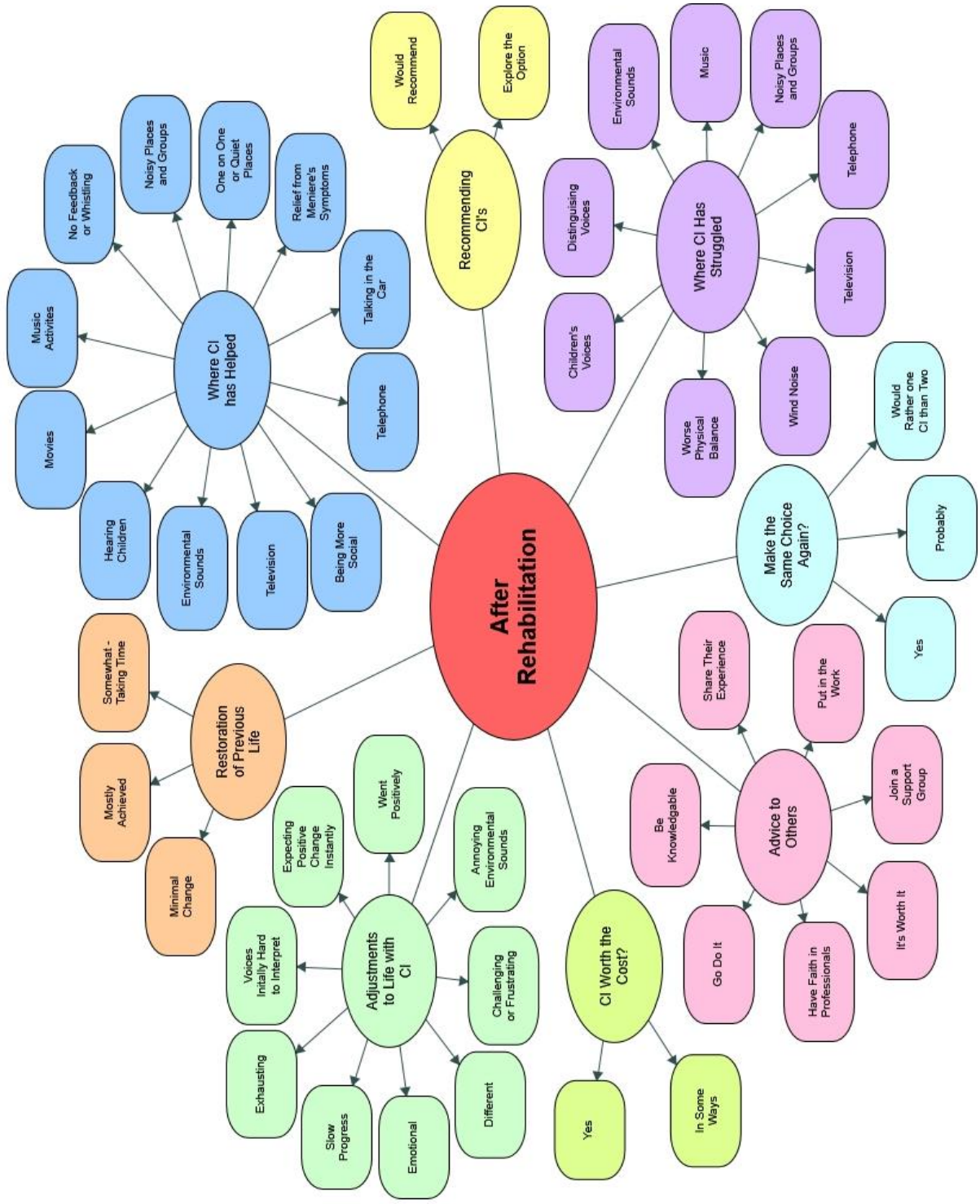


Figure 5- Thematic map of themes and sub-themes after rehabilitation

Table 7. After rehabilitation themes and sub-themes with corresponding supporting participant quotes. Themes and sub-themes are organised from mentioned most often to least often. Numbers in italitcs under themes display how many participants that mentioned those themes.

Themes	Sub-Themes	Supporting Quotes
Advice for Others *12*	Go Do it *6*	**P105** "I'd say don't muck around. Get it. Depending on the age and everything else whether or not to go on the waiting list. I'd say don't muck around. Go have it."
	Be Knowledgeable *2*	**P108** "Consider it very carefully. And do go and see either the people at the [CI programmes]."
	It's Worth it *2*	**P100** "I'm not sure, I guess it is worth it… No matter, which way you have to go but it is worth it."
	Share Their Experience *2*	**P106** " Just to share my experience…"
	Have Faith in the Professionals *1*	**P103** "Oh, you have to have faith in your medical staff and realize it's for your benefit and just go for it, because it's a lonely world not being able to hear."
	Join a Support Group *1*	**P110** "…I'm in two groups where we meet and talk about things. And they're not telling you technical things. You're just having a social discussion but it's really good."
	Put in the Work *1*	**P100** "…you have got to put the work in as well."
Make the Same Choice Again? *12*	Yes *10*	**P110** " Definitely. No hesitation."
	Probably *1*	**P111** "Oh, I probably would for simple reason. I was just going to go deaf."
	Would Rather have Chosen One CI *1*	**P109** "Yes and no. I would probably have gone one first and then gone the second."
Recommending CI's *12*	Would Recommend *11*	**P102** "I'd definitely recommend a cochlear implant…"

	Explore the Option *1*	**P108** "At least look into it, study it, yeah. And talk to them about it."
Restoration of Previous Life *12*	Mostly Achieved *5*	**P102** "…I mean, I can hear the TV better now, so well that I'm telling my father to turn it down. Going to the movies is great. Going to concerts, it's a wonderful experience. I picked up the cello and started playing it again."
	Somewhat – It's Taking Time *5*	**P100** "It hasn't totally yet but it's an ongoing thing trying to train my brain."
	Minimal Change *2*	**P111** "It hasn't changed a lot. I've got a great lot of friends who have been so supportive and helpful and understanding and it's been a big, big factor…"
Where the CI has Helped *12*	One on One Conversation or Quiet Places *10*	**P109** " One-on-one is awesome, they are great one-on-one."
	Environmental Sounds *8*	**P107** "…There's another noise that I hadn't heard before, so I did it again, and loose change in my pocket. That's the first time I would have heard that for 20 odd years."
	Noisy Places and Groups *8*	**P102** "…there were other benefits like having to talk to people, have a conversation in groups. And noisy situations, I could still have a conversation with somebody and not miss on it…"
	Being More Social *7*	**P102** "…I tend to contribute more to the conversation now than just sitting back and just listening to people. Yeah. I think also I just have to find myself comfortable with understanding people's jokes and things like that, that I haven't heard before."
	Television *6*	**P101** "It has improved. I guess watching T.V. I used to rely on subtitles quite heavily, I can get by mostly without them now."
	Talking in the Car *4*	**P105** "But I could never have a conversation in the car. Now we can have a good conversation."

	Hearing Children *3*	**P101** "Well we have got two grandchildren with us at the moment, just on holiday, and I'm finding that with them I am able to understand what they say a reasonable amount of time, where as before I would have struggled I think."
	Movies *2*	**P108's Husband** "…how was it in the pictures he other night? **P108** "I heard everything." **P108's Husband** "Oh, that's better because you couldn't hear it before."
	Musical Activities *2*	**P106** "Yes. Interestingly, music is actually slowly improving. I actually started going to concerts again."
	No Feedback or Whistling *2*	**P104** "…with an implant, you don't get the whistling."
	Relief from Meniere's Symptoms or Tinnitus *2*	**P107** *Referring to experiencing tinnitus* "Right up until I got my CI."
	Telephone *2*	**P102** "Well, I've at work I use my cellphone a lot for phoning, really good."
Worth the Cost? *12*	Yes *10*	**P101** "I do not think you can put a cost on things like your hearing, it is just if you want to participate in normal life you do what it takes to do it."
	In Some Ways *2*	**P109** " Yes and no. I'd be pretty much 60, 40 on the yes side of things."
Adjustment to Life with CI and Post Switch on Experience *11*	Slow Progress *8*	**P103** "Slowly. Sometimes, I've felt a bit frustrated, like it's not happening quickly enough."
	Challenging or Frustrating *6*	**P111** "No, I wasn't losing hope, but you try and hear things and you just can't and it's just so frustrating because I could have probably heard them before."
	Exhausting *5*	**P109** "I pick up a bit more but now I'm, since the op I've been mentally drained every day. Every day I'm just mentally exhausted.

		Because I'm trying to take in what's being said and hold it. Whereas before, because I didn't understand it I didn't have to hold it. So it can go in one ear and out the other."
	Expecting Positive Change Instantly *4*	**P105** "First three months I really wondered what the hell I'd done. It was very difficult… as I thought I was going to hear straight away…"
	Voices Initally Hard to Interpret *3*	**P100** "But you know when I first got turned on. Wow you know. But it was difficult trying to discern different voices, they all sounded like they are all mumbling."
	Annoying Environmental Sounds *2*	**P102** "Initially when I first had my cochlear implant, I was so annoyed with the sound of the leaves, like, Oh, my God. Is that what people hear every day? Oh, no. I'm not having that!"
	Different *2*	**P104** " Well, initially it was quite different. It's funny, sounds, and it's something you can't explain actually..."
	Emotional *2*	**P111** "Because it's been a very emotional, hard emotional journey."
	Went Positively *1*	**P106** "…switch on went pretty well. We had speech recognition from get go and in fact could hear a phone call through the thing from get go…"
Where the CI has Struggled *10*	Music *7*	**P110** "Okay. Music. Listening to music. I miss that."
	Telephone 6	**P100** "I still have difficulty I can't hear on the telephone, and it's just garble."
	Noisy Places and Groups *4*	**P106** "…so putting the amplified left ear together with the implant, it's pretty good except in a noisy environment."
	Environmental Sounds *3*	**P109** "Well, it's even, driving is a pain in the butt because it's so quiet. And I can't hear vehicle noise but I'll get the road noise coming through and it drowns everything out."
	Wind Noise *2*	**P101** "There are some things that are difficult like the wind cancellation on these things is

		nowhere as good as it is on these, it is a pitty…"
	Children's Voices *1*	**P103** "Now I've got five little great-grandchildren, or three of them, or four. Four. No, but three of them I don't hear very well..."
	Distinguishing Different Voices *1*	**P100** " I'm still trying to get it tuned so I can distinguish the voices."
	Television *1*	**P108** "…The music overlay over the voices, it's still problematic, I can't understand it."
	Worse Physical Balance *1*	**P103** "…But the only thing, as I said, is just my balance. I'm just a bit disappointed in that respect, but I can still walk. So that's okay."

The data displayed in Table 7 show the participants' experiences via themes and sub-themes after their rehabilitation with a CI. Initially there was an adjustment process after switch on, participants predominantly found this a challenging/frustrating slow process and were often left exhausted in the weeks following. As more time passed participants experienced instances where their CI positively impacted their life. Most commonly one on one conversation improved significantly and some also found it assisted them in noisy places and groups. More noticeable environmental sounds were noted, they ranged from hearing the birds to the rattling of change in a pocket.

Collectively, the CI enabled some participants to engage in more social activities, where they were not doing so pre-implantation. However, the CI had areas where it struggled to perform as adequately. The most common drawbacks were disliking the sound of music and struggling to understand others on the telephone. There was some confliction in reporting, as some participants found the CI did not perform well in noise, where others acknowledged it did. After the challenging time post switch on, some participants eventually

felt restoration of their previous life, while others mentioned it was a work in progress. Only two participants felt that CI had minimal change when compared to their experiences with HAs.

Almost all participants said the CI was worth the cost. For the two that did not agree with the consensus, they acknowledged that it was worth the cost in some ways. This was due to their mixed feelings of success and failure. Since almost all participants found an improvement in their lives, all but one participant would recommend a CI with no hesitation. The other recommended the option be explored. To accommodate the recommendation, the most common advice for others in the same situation was to just go do it. Some participants even suggested if they knew about CIs earlier they would have had the implantation earlier and encouraged others to not wait.

Finally, participants were posed with a question “Would you make the same choice again?” ten out of twelve participants showed no hesitation and said they would. For those who hesitated, their answers were not no. For one participant he wished he had rather chosen one CI instead of having two done at the same time, and the other participant said a convincing probably.

Throughout Journey

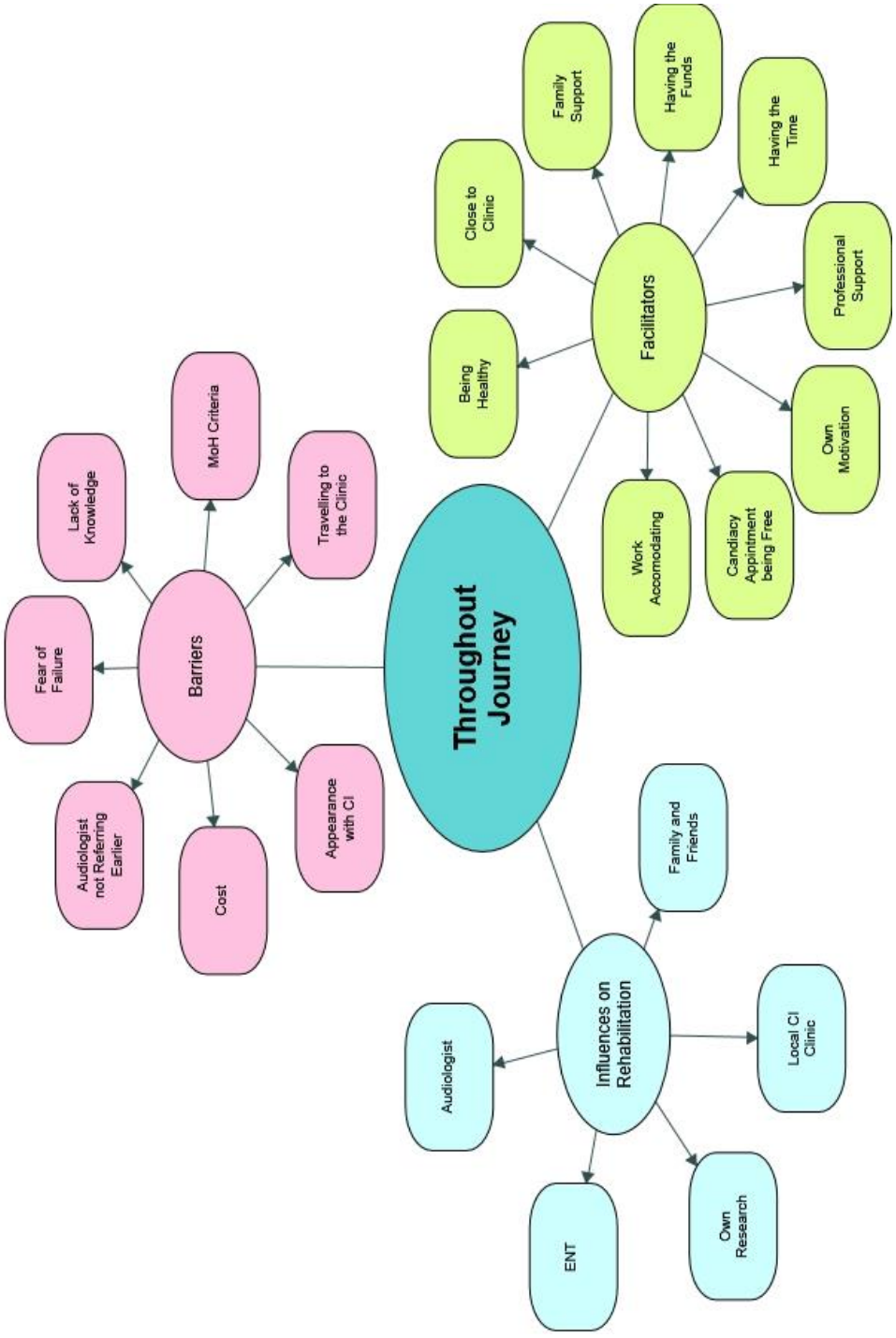


Figure 6– Thematic map of themes and sub-themes Throughout Journey

Table 8. Throughout journey themes and sub-themes with corresponding supporting participant quotes. Themes and sub-themes are organised from mentioned most often to least often. Numbers in italics under themes display how many participants that mentioned those themes.

Themes	Sub-Themes	Supporting Quotes
Facilitators *12*	Own Motivation *8*	**P110** "Well, it was my priority. So, everything else didn't matter."
	Professional Support *5*	**P109** " I think having [the rehabilitationist] and being able to talk to her. And knowing she's got them, and it was knowing someone else that had them."
	Having the Funds *4*	**P106** "The money wasn't a concern."
	Being Healthy *2*	**P103** "Just thankfulness, I suppose, that it's really happening to me and that I was physically well enough."
	Close to Clinic *1*	**P101** "I do not know. I think being [local] made a huge difference. If I had been in [distant places] you know..."
	Family Support *1*	**P103** "Oh, my family perhaps helped me, as well. They'd just say, 'Well, if you don't have it done, Mum, you'll be deaf in a short time.' So, I was, 'Okay, I'll go for it.'"
	Having the Time *1*	**P111** "…I had the time, all the time in the world. It wasn't as if someone had taken time off work or anything…"
	The Candidacy Appointment being Free *1*	**P104** "…the idea that the public service actually did the assessment probably helped, if it didn't cost me that much to go up there and get assessed…"
	Work Accommodating *1*	**P101** "…the other thing was because I was at work, I could take leave and be supported for it."
Influences on Rehabilitation *12*	CI Clinic *11*	**P105** "They were good, exceedingly positive, and that's why I was so encouraged. They were very positive in there…"
	Audiologist *10*	**P110** " I spoke to a chap [locally] in the audiology department and he was very

		knowledgeable and helpful. He started me on the path."
	Own Research *8*	**P102** "I looked on the Internet quite a bit. Tinnitus Talk is an online forum for people to talk about the experiences. I researched whether some people had done a cochlear implant and whether that had reduced the tinnitus…"
	Family and Friends *5*	**P108** "…I thought, it's good enough for a war vet, it might be good enough for me."
	ENT *3*	**P101** "…at one point in the 10 years of my hearing I had been referred back to [the ENT] and he had just said, 'Well, the reality is that the way you are going at some point if you want to keep hearing you are going to need an implant.'"
Barriers *10*	Cost *8*	**P109** "I managed to, it was tough going, we managed to scrape the money together to get it."
	Audiologist not Referring Earlier *2*	**P105** "…But the thing that disappointed me more than anything was the audiologist just wouldn't recommend me because they're too busy trying to sell hearing aids…"
	Fear of Failure *2*	**P103** " No, it was only if it didn't work, but I tried not to keep that. I tried to push that back out of my head and I was just so privileged and able to have it done."
	Lack of Knowledge *2*	**P108** " Lack of knowledge probably. I didn't know about the program basically. I had heard of the implant itself but not the program."
	The MoH Criteria *2*	**P102** "Probably the Ministry of Health guidelines was what stopped me."
	Travelling to the Clinic *2*	**P104's Wife** "So the travel has been something that, it's been okay, but it does consume the air, and the cost involved to get up and down." **P104** "Yeah." *In agreement.*
	Appearance with CI *1*	**P101** "…there are barriers in terms of seeing people with something funny on the side of their head like a flag that they are not mainstream, that there is something odd about them."

The data displayed in Table 8 show the participants experiences via themes and sub-themes throughout their journey. The overwhelming majority of participants mentioned that cost was a barrier in them undergoing rehabilitation and treatment. All other sub-themes had less consensus, showing a lot of variability between experiences. What facilitated the participants to seek treatment and persist with their rehabilitation was predominately reflected by their own motivation. Their own motivation could also be a contributing factor into why some participants conducted their own research on CIs when deciding on their rehabilitative needs. Other participants found professional support to be the factor that facilitated their journey the most. Professional support was also acknowledged and related to the influences on rehabilitation, with the CI Clinic and audiologist being the most influential on their journey.

Participant Validation of Themes and Sub-themes

Five of twelve participants responded via email in response to whether the themes and sub-themes described their own journey. All five indicated the range was comprehensive and included their own experience. Two participants had additional points; Participant 101 commented: “My only comment is that the outcome responses are rather muted, I would have expected a high percentage of very positive feedback. In my own case a recent readjustment with input from a visiting consultant was very helpful and has noticeably improved my ability to understand what others are saying”. Participant 106 commented: “Under choice of device MRI compatibility came into my thinking.” Overall the responses indicated that the themes represented the respondent’s journey well.

In summary, this chapter presented; participant demographic and audiological information, questionnaire data, findings of main themes and sub-themes in each stage of the journey supported by participant quotes, validation of themes via participant response. The following chapter will discuss the study’s findings with previous research, the questionnaire

data, the implications of the findings from a clinical and social perspective, limitations of the study and suggestions for future research.

Discussion

The first aim of the present study was to develop a better understanding of the patient journey for adults transitioning from HAs to a CI who privately funded their rehabilitation. As presented in the results chapter, the journey was categorised into four main stages: Before, During, After and Throughout Journey. Within each stage various themes were discovered; each main theme will be discussed below with relevant literature, along with a summary and discussion of overall findings. The second main aim was to observe how participants funded their CI privately to try and provide that information to assist funding for future recipients; this will also be discussed below.

Before Rehabilitation

Where hearing impairment has affected their life. The results from the present study were consistent with previous research showing that HI affects many areas of individuals' lives. For the present study this was most prevalent in social situations and at work. Stark and Hickson (2004) studied 93 older individuals, with no prior experience with HAs and varying levels of HI, using hearing specific QOL questionnaires. Their conclusions were that noisy situations were the most impacted by HI, followed by listening to the television and radio. The present study showed similarities in noisy or more social situations, but television was rarely mentioned. Since Stark and Hickson (2004) was conducted 16 years ago, these differences could be attributed to the improvements in technology to assist with television and radio. Many participants mentioned their difficulties in the workplace and in some cases, their HI limited their job opportunities. There is evidence to suggest that there is an increased likelihood of individuals with HI to encounter difficulties and higher risk of work-related injury in their workplace in comparison to their colleagues with normal hearing, even those with a mild HI (van Til, Kramer, Anema & Goverts, 2016). A qualitative study in Norway by Svinndal, Jensen and Rise (2020) interviewed 21 individuals with varying levels

of HI and device use, nine participants had a severe loss and four used a CI. They concluded similar results and went on to suggest that workplaces need to be more accommodating to HI individuals and offer occupational rehabilitation services to help combat fatigue commonly experience by these individuals. A review by Manchaiah and Stephens (2013) list a broad range of positive and negative consequences of HI that include: difficulty with communication, social withdrawal, reduced job performance and reduced interpersonal interactions – all of which were encountered by the participants of the present study.

Social isolation. Many of the participants experienced HI affecting their ability in social situations, which for some can lead to social isolation and/or depression. The present study revealed that almost all participants experienced either some form of social isolation or depression due to their HI. Research also confirms this is not an uncommon experience for those with HI. Weinstein and Ventry (1982) were the first to explore this relationship in veterans. They compared audiometric data with subjective social experience (e.g. loneliness and reduced interest in social activities) and discovered a correlation between HI and increased risk of social isolation behaviours. More recent research also supports this. Pronk, Deeg and Kramer (2013) conducted a 4-year longitudinal study on 996 older adults (63+ years) in Amsterdam measured using multiple questionnaires and speech-in-noise testing. To measure HI, they used the hearing disability scale originating from the Organization for Economic Cooperation and Development disability indicator (McWhinnie, 1979) and a digit triplet speech-in-noise test. The De Jong-Gierveld scale was used to measure for emotional and social loneliness (De Jong-Gierveld & Kamphuls, 1985) and the Center for Epidemiologic Studies Depression Scale (Radloff, 1977) for measuring depression. They revealed a relationship between poorer hearing status and higher (poorer) scores for emotional and social loneliness. Their results were inconclusive when comparing the test battery results with the self-reported depression scores. The present study acknowledged

several participants experienced social isolation and/or depression; they self-reportedly linked it to their HI i.e. participant 107 commented "A lot of people you knew in your younger years, I'd caught up with them again… nine times out of ten, you try and talk to them. But I bugger off home." There is research that indicates higher rates of depression in the HI community. A study by Ishine, Okumiya and Matsubayashi (2007) in Japan involved 434 older adults (65+ years) with varying HI levels and hearing device use. They used 2,170 age and sex matched individuals without HI for comparison. Participants with HI were segregated into four groups based on their self-reported hearing level scores from 'hears well' to 'can scarcely hear'. They used the Geriatric Depression Scale (GDC) (Yesavage et al., 1982) to measure for depression. Their conclusions revealed that there was a statistically significant relationship with HI and depression. A follow up cohort study by Saito et al. (2010) in Japan of 580 older adults discovered similar results. They segregated the participants in two groups (no hearing handicap and with a hearing handicap) based on the Hearing Handicap Inventory for Elderly (HHIE-S). Participants took the GDC and had face-to-face interviews to establish depressive symptoms. When comparing the two groups, those with a hearing handicap had a maladjusted odds ratio of depressive symptoms of 2.45 (95% confidence interval [CI]=1.26–4.77). This indicated that those with HI were 2.5 times more likely to experience depressive symptoms. Several participants had discussed that their HI was a direct influence on their mental wellbeing and some acknowledging depressive symptoms. Outside of Japan, another study in the USA amongst HI adults had similar findings (Li et al., 2014).

Hearing impairment's effects on family. As mentioned above, the participants experienced hardships and difficulties with their HI. However, they were not the only ones to encounter difficulties; the effects were felt by friends and family. The participants revealed their loved ones would become frustrated and communication would breakdown or be more difficult. For example, participant 101 commented "…I am aware especially with my wife

that is a really irritating thing [asking for her to repeat] so I tend not to. It is easier not to understand than to ask her again." For some participants this breakdown in communication led to their social isolation; participant 102 commented "…when you are being misunderstood you don't have a good conversation with people. You tend to isolate yourself." A systematic review of 24 studies by Kamil and Lin (2015) supports some of the themes identified in the present study. The review indicated that there was an increased burden of communication, restricted social life, poorer QOL and relationship satisfaction experienced by those with HI. The present study did not explicitly include direct input from partners or other communication partners. Although partners were present in some interviews and expressed their thoughts and feelings. Therefore, most of the sub-themes formed were based on the participants' observation of how their partner felt and potentially are not indicative of how their communication partners really felt.

Communication strategies and coping mechanisms. Due to the difficulties someone with HI faces, they can develop communication strategies and coping mechanisms. The participants in the present study developed a wide range of maladaptive and adaptive coping mechanisms. Adaptive strategies are behaviours that improve communication (e.g. asking for repeats) and maladaptive strategies are strategies that negate communication (e.g. pretending to understand what was said) (Gomez & Madey, 2001). As mentioned in a quote above from participant 107, sometimes asking for repeats can cause frustration with loved ones so some communication strategies start being avoided. This could also lead to an increased reliance on maladaptive strategies. The majority of participants in the present study showed more adaptive strategies, with lip reading and asking for repeats being the most common. An interview-based qualitative study in the UK of 14 older HA users (similar in age to the present study) with varying degrees of HI, ranging from mild to severe. They found few coping strategy themes that reflected the findings of the present study. Their sample

population predominantly used maladaptive approaches and withdrawal techniques to cope with their HI (Holman, Drummond, Hughes & Naylor, 2019). Their study focused largely on the experience of fatigue and HI which might have primed the participants to discuss more maladaptive approaches. A study by Domagała-Zyśk (2019) of 72 individuals with HI in Poland revealed roughly two thirds of their participants showed adaptive techniques and falls more in line with what the present study suggests.

Motivation. An important factor in an individual's journey is their motivation to seek rehabilitation. Whether it is getting the first pair of HAs or transitioning to a CI, motivations play an important role in making that step. The most predominant research focusing on motivation of those seeking hearing rehabilitation is in the adoption of HAs. Ridgway, Hickson and Lind (2015) conducted a questionnaire-based quantitative cohort study in Australia of 253 adults of which 160 adopted HAs during the study. The treatment self-regulation questionnaire (Levesque et al., 2007) was adapted to replace words such as medication with HAs. This was used to measure motivations for HA adoption. The wishes and needs tool (Dillon, 2012) was also used to measure desire for HAs. After segregating participants into two groups (HA adopters and non-adopters), they tested each independent variable for associations with HA adoption using chi-squared for categorial variables and Student's t-tests for continuous variables. The results revealed that autonomous motivation, perceived hearing difficulty, and poorer hearing were the major motivating factors for HA adoption in their sample population. The findings were very similar to the experience of the present study's participants, with not hearing well enough being the most common motivation. Further, within the 'facilitators' theme in Throughout Journey, 'own motivation' was overwhelmingly the most common reason. Stark and Hickson (2004), a study mentioned earlier in the discussion, also revealed that approximately one third of their sample population adopted HAs because of their own motivation. Their results differ from the present study in

that most of their population said external encouragement from family was the biggest factor in HA adoption, which was observed in fewer of the present study's participants than self-driven reasons. However, there may be some differences in what influences HA and CI adoption. Those seeking hearing rehabilitation by using HAs are more likely to be seeking help with their HI for the first time. Whereas those seeking hearing rehabilitation by using a CI are more likely have prior experience with HAs. This prior experience of undergoing a form of hearing rehabilitation could influence adoption and motivations.

Tipping points. Along with motivating factors, for others there was a single tipping point that was the main contributing factor in progressing with a CI. For the majority of participants, the sheer day to day struggle with HI building up overtime acted like their tipping point for progression. For others the events causing that tipping point were more spontaneous, such as a split with a partner or failed middle ear surgery. The consensus from the present study appears that most of the time it is a culmination of factors and the ongoing struggle with HI that leads to the tipping point.

During Rehabilitation

Perceived options. For almost all participants in the present study, they perceived that there were no other options. When questioned about their available options, many looked confused as to why that question even needed to be asked. For the ones that were not puzzled, they simply stated it was either the CI or just stay how they are. There was a consensus amongst everyone that for them to improve their quality of life, the CI was the only option forward.

Reasoning for private care. There is limited public availability for CIs in NZ as mentioned by J. Mustard (personal communication, May 20, 2020) of only 40 implantations for adults per annum in NZ. Therefore, going private may be the only option for many unless

they are willing to spend years on the waiting list. Participant 101 commented “I mean it is an option [the waiting list] that is there to make people feel as though they are not desperate, but it is not actually a realistic option.” Overwhelmingly the reason for electing private care was because the waiting list is an unrealistic option. In all cases the CI team discussed the unrealistic wait times and recommended the participant to go privately. For the participant that was on the waiting list, they felt as though they had wasted time trying the public option. Participant 105 commented “…they [CI team] said, "No, you're not moving up your list. You're staying very stagnant in the middle of the list." It's not bloody good. I wished they'd told me that in the first place. If they'd told me I wouldn't have wasted two and a half years.”

Factors in choosing devices. Many participants relied on professional advice for many decisions made in their rehabilitation. Within themes such as motivation, tipping point, reason for private care and facilitators, professional opinion was common amongst the sub-themes’ rhetoric. One of the main reasons participants chose between different CI manufacturers was because of what professionals suggested. A study by Kahana, Yu, Kahana and Langendoerfer, (2018) used a sample population from a previous longitudinal study (Kahana, Kelley-Moore & Kahana, 2012); the final numbers included were 806 participants with an average age of 77.8 years. They measured patient communication satisfaction using a revised four item patient-physician communication satisfaction scale to evaluate satisfaction with their primary care physician. After using multiple hierarchical regression analyses, their results concluded that their sample population had very low self-advocacy with 87% of respondents reporting that their physician advocates on their behalf. These findings have also been observed in Foss (2011) who also found low self-advocacy among their participant pool. This could provide some reasoning on why many of the participants in this study trusted professional advice. It is potentially due to low self-advocacy in making decisions over

healthcare, which was reflective in how some participants made decisions throughout their journey.

An equally popular sub-theme for CI device choice was features and reliability of the product. Chundu and Stephens (2013) conducted a qualitative study of 43 adults and 19 children in the UK to determine what factors influence CI device choice. The study concluded the most prominent answer was appearance. Only one participant in the present study was concerned about appearance, this difference is likely to do with the average age difference 69 ± 10 years for the present study and 48.6 ± 20.7 years for males and 54.8 ± 18.7 years for females in the adult sample population of the UK study. There may also be regional differences such as more public funding, cultural norms and differences in rehabilitative counselling, contributing to what was observed between studies.

Financing treatment. Ways of financing CI rehabilitation was diverse and for many it was the most substantial challenge they faced in their journey, noted as the most prominent barrier discussed in the Throughout Journey section. Because this study only included private patients, the most common funding method was sourcing from their own savings. For some funding was not a concern e.g. participant 106 commented “The money wasn't a concern.” For others finding ways of financing a CI was a difficult e.g. participant 109 “… it was tough going, we managed to scrape the money together to get it [funds for the CI].” With a price tag of roughly $50,000 NZD a privately funded CI is out of reach for many candidates and several of the present studies participants relied on the generosity of others and foundations to fund a CI.

Feelings about going ahead. Once participants had established the decision to proceed with a privately funded CI, they expressed various thoughts and feelings. Most were excited or positive about the potential life a CI could offer them and were hopeful about the

outcomes (discussed in 'hopeful outcomes' below). Those who were more apprehensive tended to be most concerned about surgical outcomes and if they were going to be the statistical anomaly with a failed surgery. Overall, most participants' feelings gave a sense of hope for their future and the possibilities to take back what they were missing, most notably in social interactions where participants highlighted they had the most trouble (discussed earlier in the Before Rehabilitation section).

Hopeful outcomes. Along with positive feelings the participants also expressed hopeful outcomes with their CI use. The overwhelmingly most common hope was to hear better. For example, participant 107 commented "…Hearing a lot better and trying to be in the conversations…". The majority of participants no longer could get effective amplification from their HAs and CIs offered a hope to be able to hear things they were missing. This was also a driving factor in many participants motivations (discussed earlier in Before Rehabilitation) for pursing a CI; the need to hear better was the most common sub-theme. Since most participants experienced social isolation as discussed earlier in Before Rehabilitation, the hope of being able to hear better was often linked with the hope of being more socially involved. For example, participant 105 commented "…So I could hear noise, or I could hear raffle numbers and speeches and then sort of get myself involved a bit more."

Expectations. The participants' expectation**s** of the CI were mostly high and realistic, no participants had low expectations. Some participants had high expectations partly due to the cost of a CI. For example, participant 110 commented "…when you pay money yourself you expect instant improvement. You're buying something, you want it to work..." and others high expectations were not met post switch on. For example, participant 111 "My expectations were a lot higher than the actual results…" Those who had realistic expectations would often mention a hearing professional having assisted with lowering previously high expectations. For example, participant 106 "… [ENT] was pretty keen on talking down my

expectations…" There is an absence of research evaluating CI expectations. Although a study by Mäki-Torkko, Vestergren, Harder and Lyxell (2015) of 120 unilateral CI users in Sweden (mean age 61.1years) measured expectations before surgery and if those expectations were met within 12 months post-switch on using a mailed self-developed questionnaire. Their findings suggested that there was an increase in overall wellbeing and life satisfaction post-CI which met most pre-implant expectations.

The only areas where expectations were not met was with music and phone use. The dissatisfaction with music and phone use was consistent with the present study where over half of participants struggled with these areas post-implantation, as will be discussed later in further detail in After Rehabilitation. Saunders, Lewis and Forsline (2009) conducted a study with 60 new HA users over the age of 55 years testing different pre-fitting and follow up counselling methods. Their results indicated that having high or positive expectations before fitting suggests a higher likelihood of more positive outcomes. A study performed in Denmark by Bille and Parving (2003) with 805 older adults who were new to HAs, used the Expected Consequences of Hearing Aid Ownership questionnaire (Cox & Alexander, 2000) to examine HA expectations in their sample population. Their participants tended to have high or very positive expectations about HAs, some of these expectations were unrealistic regarding what HAs can achieve. This can also be observed in the present study: almost all participants experienced a positive outcome, and none indicated low expectations.

After Rehabilitation

Adjustment to life and post switch on experience. The early post switch on experience and life adjustment were challenging and/or tiring for almost all participants. Participant 102 commented "Each day is challenging. I mean, each mapping session is a challenge. Every three months you've got a new mapping session and there will be new things that you have to try and work out." Most of the participants acknowledged that it was

the most challenging immediately post-switch on (<3 months), with some having recalled questioning if things would improve. Mäki-Torkko et al. (2015), previously discussed in During Rehabilitation section, measured various outcome experiences via questionnaires. Their findings for initial feelings post-switch on were similar to the present study, with many reporting fatigue and difficulty differentiating sounds. Many of the participants in the present study experienced slow progress and feeling as though progress should have been quicker. This could be attributed to the older demographic of the present study and many participants encountering HI at a younger age (longer duration of deafness), both of which have been shown to influence speech perception test scores negatively (Holden et al., 2013; Williamson et al., 2009). Sladen and Zappler (2015) conducted a CI user study between 20 adult CI <60 years and 20 adults >60 years to see the differences between outcomes. They assessed speech perception, music perception and administered a health related QOL questionnaire. Their results indicated significant differences between the groups for speech and music perception. However, the QOL measure showed a less substantial difference between the groups. Their conclusion was that the areas where older CI users struggle more are task specific and not global.

Where the CI helped. Qualitative research surrounding what listening environments and situations where a CI has helped is limited. Most research is either objective in the form of speech testing or subjective measures using various QOL questionnaires, with general congruence of improved overall QOL and improvement in speech testing post CI (e.g. Aimoni et al., 2016; Holden et al., 2013). The present study's participants most notably saw improvements in quiet and with environmental sounds, this was also reflective in their NCIQ scores which are discussed in more detail below. These results are consistent with studies (e.g. Looi et al., 2011; Häußler et al., 2019) that measured outcomes with NCIQ where basic sound perception subdomain (sounds in quiet environments and environmental sounds) score

higher than advanced sound perception (more complex/noisy environments). The majority of participants also acknowledged the CI helped in them becoming more sociable. This was an important improvement since becoming more social was reflected in some participants' hopeful outcomes discussed earlier in During Rehabilitation and relates to the social isolation theme discussed in Before Rehabilitation.

Where the CI struggled. The sub-themes revealed a diverse range of areas where the CI helped, this diversity was also observed in areas where the CI struggled. Listening to music and talking on the phone were predominantly the most difficult among participants. Poor music enjoyment has been thoroughly researched for CI users highlighting a major area in need of improvement for future technologies, as discussed in the introduction (Limb & Roy, 2014; Bruns et al., 2016). A study conducted by Anderson et al. (2006) using a custom designed survey and 196 respondents showed that 71% of CI users were able to use a landline telephone with 54% reporting being able to use a mobile phone. Respondents acknowledged that familiar speakers and familiar topics were helpful when using the phone. The participants in the present study noted similarities with a familiar voice being easier to understand on the phone. Mäki-Torkko et al. (2015) showed in their results that expectations surrounding music and phone use were not met in CI users. They advised that more counselling is needed to affirm more realistic expectations in these areas. Post-implantation musical training is an option for CI users who want to increase their enjoyment for music. Looi et al. (2012) revealed that music training might have benefits on improving outcomes in complex listening environments and music enjoyment.

In the present study there were many areas where some participants saw improvement, and others did not. This was most notable in responses to noisy environments like restaurants and sporting events. However, when questioned further many participants

suggested that although the CI still struggled in those environments, it was still an improvement over their HAs.

Restoration of previous life. For all participants there was a goal to hear better and therefore a hope to restore their previous life or what had previously been missing. For most participants this was somewhat achieved or mostly achieved with only two experiencing minimal change. A similar study conducting open interviews in Sweden involving 17 participants with a CI discovered a theme 'coming back to life' which resembled the findings of the present study. They noted in this theme that participants felt as though they were more socially connected than before and more involved in their environment which gave them a sense of coming back to life (Hallberg & Ringdahl, 2004). The participants in the present study felt as though there was restoration of what was missing previously, even if it was not entirely achieved.

Cost analysis, recommendation and advice. Participants compellingly supported the idea that a CI is worth the cost. Only two participants hesitated in answering if it was worth the cost, they concluded it being worth it in some ways. For example, participant 109 commented "Yes and no. I'd be pretty much 60, 40 on the 'yes' side of things." Given that for many participants' the main barrier was cost, it can be assumed that the CI made a significant difference in their lives to justify the expense. For example, participant 101 "I do not think you can put a cost on things like your hearing, it is just if you want to participate in normal life you do what it takes to do it". All participants were willing to recommend a CI to someone in a similar position, once again highlighting the positive impact a CI has made in their lives. The most prevalent advice the participants had for others was to just go do it, with some wishing they had done it sooner themselves. Finally, almost all participants had no hesitation on making the same choice again. Participant 109 was in a difficult situation with wishing they had gone with just one CI instead of two because pre-implantation he had

adequate low frequency hearing and in hindsight would have opted for a bimodal fitting. The other individual who was hesitant ultimately decided they would probably make the same choice again, although they had a challenging time adjusting to their CI.

Throughout Rehabilitation

Barriers. The overwhelming barrier faced by this group of participants was cost. As mentioned previously, there were various funding methods and for some gathering the funding necessary was not a simple task. This is not an uncommon experience amongst the evidence for those interested in a CI, not just in NZ, but worldwide. A study from the USA that analysed and proposed the reasons for the poorer uptake of CI's in the USA in comparison to other developed nations found cost being a major factor, along with minimal awareness and lack of referral from hearing professionals (Sorkin, 2013). Out of the seven barriers Sorkin (2013) discussed, three were consistent with the participants' experiences from the present study; many of the barriers were region-specific to the US healthcare system. Cost being a substantial and prevalent barrier is also highlighted in other regions of the world including research from Japan, with adults having to fund or partially fund their children's CI (Okubo, Takahashi & Kai, 2008) and similar barriers from individuals seeking first time hearing rehabilitation via HAs or hearing communication programmes in Australia (Laplante-Lévesque, Hickson & Worrall, 2010). Evidence presented in Bierbaum et al., (2020) is somewhat contradictory with no mention of cost as a barrier but showed support for the other themes e.g. lack of knowledge. This observed difference is likely due to Bierbaum et al., (2020) including publicly funded CI in Australia and the UK, whereas the present study included individuals that had to self-fund.

Another barrier that was experienced by 2 participants was that the audiologist did not refer early enough. As previously mentioned in the Before Rehabilitation section, external encouragement was a motivating factor for several participants which involved

encouragement from hearing professionals. Participant 105 commented "…But the thing that disappointed me more than anything was the audiologist just wouldn't recommend me because they're too busy trying to sell hearing aids…" Looi, Bluett and Boisvert (2017) investigated the referral rates for postlingually deaf adults for CI candidacy assessments. They conducted the study at an audiology clinic that offered HA services and no CI services. The study was in two parts: online clinician questionnaire and retrospective record review of clients. They determined with these records which clients met audiological criteria for CI referral. Their results proposed 16 (89%) of participants discussed CIs with their audiologist and 11 (61%) were referred for CI evaluation. The reasons for not referring were predominantly because the client showed negativity towards CIs. They discussed that the clinician's decision-making process is complex, and more tools and resources are needed in assisting this. These findings were supported in Bierbaum et al. (2020) as they identified lack of knowledge, low confidence in identifying potential candidates, and therefore lack of confidence in referring among hearing professionals. Hence the importance for clinicians to listen to their clients' needs and be up to date with current audiological referral criteria (discussed in further detail in Clinical Implications section).

Facilitators. What predominantly facilitated participants through various stages in their journey was their own motivation. As previously discussed, motivation was predominantly the need for the participants to hear better, which is a self-motivating factor. This is also observed in Bierbaum et al. (2020) who found that a desire for better hearing and improved communication was one of the most common facilitators in CI uptake. The study by Ridgway et al. (2015) showed that the largest contributing factor for HA uptake was autonomous motivation which further supports the present study's findings. Bierbaum et al. (2020) also found that another major facilitating contributor to CI uptake was professional and family support. This was observed in the present study's findings and the second most

common facilitator mentioned was professional support. Family support was not a commonly reported facilitator in the present study, with only one participant explicitly acknowledging this. Although many participants appreciated their loved one's support, it did not appear to be a significant influence on their rehabilitative decisions.

Influences on rehabilitation. The influences on rehabilitation were broad but with most pertaining to hearing professionals. The audiologist was the most common influence before the rehabilitative journey, often being the first point of contact and knowledge about CIs. The CI Clinic was the most common influencer before rehabilitation and throughout the rehabilitative process, they provided the bulk of knowledge about expectations and general information regarding CIs. Most participants also sort information online or in brochures to help with understanding CIs and helping choose what device.

Questionnaires

Most participants in the present study were >1.5 years post switch on. There is evidence indicating that speech perception (holden et al., 2013) and QOL plateau earlier. Häußler et al. (2019) followed 61 adult unilateral CI uses from pre-implantation to 24-month post-implantation conducting the NCIQ at various intervals. Their results indicated that QOL scores did not significantly change after six months. They also noted a 6-month plateau with Freiburg Monosyllabic Speech test scores. This study indicates that the improvements six months post switch on might be less noticeable and CI users might continue to struggle in more difficult situations, regardless of time post switch on.

When comparing the present studies NCIQ results with the NCIQ results for NZ recipients in Looi et al. (2011), some similarities and differences can be observed. The present study's NCIQ mean scores for each subdomain ranked from highest to lowest were; speech production, basic sound perception, social interaction, activity limitations, self-esteem

and finally advanced sound perception. The similarities were the highest and lowest scoring sub domains. Where they differed was the present study's participants' mean score for basic sound perception was the second highest, whereas the results in Looi et al. (2011) had basic sound perception as fourth. Their mean subdomain scores were also higher in every category when compared to the present study; most notable was in social interaction with a mean difference of 10.4. The similarities observed support that privately funded CI users likely have similar outcomes post-implantation when compared to publicly funded CI users. However, more research needs to be conducted for an accurate comparison.

Overall as a collective the NCIQ subdomain scores obtained from participants supported the results from the thematic analysis. Basic sound perception scored second highest and many participants noticed an improvement in hearing environmental sounds post CI along with speech in quiet. The worst scoring subdomain, advanced sound perceptions, contains several questions about music. The participants acknowledged during the interviews the CI struggled most when listening to music, so the low scoring in that subdomain supports what was observed in the interviews. Both participant 109 and 111 struggled the most across all areas post-implantation; they were the only participants hesitant about making the same choice again. This is reflective in their scores. Participant 109 scored the worst in every subdomain except speech production. Participant 111 mostly scored in the lower quarter in almost all subdomains. When analysing the AQoL-6d results the picture becomes clearer for participant 109. They had the lowest score by a significant margin (11 points) and expressed a lot of difficulties pre- and post-implantation in the interviews. He held a lot of regret towards having bilateral implantation and wished he had chosen a bimodal fitting. He expressed that many sounds he used to hear with HAs (car engine noise, bass in music) he could no longer hear with his CIs and this was upsetting for him. Participant 111 had one of the highest scores, so her experience documented in the AQoL-6D is likely separate from

their difficulties she expressed with her CI. Her reported difficulties could be exacerbated by her high expectations pre-implantation that were not met post-implantation.

Main Findings Summary

For all participants their HAs were not performing their hearing needs adequately, this largely reflected in their inability to contribute how they wanted socially. Not hearing well enough drove many to their tipping point to progress with alternative options to HAs. All participants felt like this only option forward was a CI, this was main reason for getting one. The most prominent barrier was cost. Funding methods were diverse and for most completely self-funded. The participants largely held positive views towards CI before and after implantation, although post switch on was a challenging time. In the end the CI was worth it. Throughout the journey participants acknowledged the trust in professional advice and often relied on them for their healthcare decisions. Lastly, the sub-themes highlighted the diversity and individuality of everyone's journey, emphasising the need for patient-centred care.

Clinical and Social Implications

One of the major findings discussed in the present study is the integral role of the audiologist and other hearing professionals in the client/patient's journey. Almost all participants said the audiologist was a major part of their initial knowledge of CIs and was a key starting point for their transition to CIs. However, not all participants said their audiologist was helpful at kickstarting their journey; a few acknowledged that the audiologist took too long to recommend CIs. A common element seen within various themes across the whole journey is a trust in the professionals, implying that if professionals are not well equipped with the appropriate knowledge then their clients will ultimately lack the information and advice needed to make the most informed decisions about their healthcare. It is crucial for professionals to keep up to date with current research and referral criteria, and to not be afraid to ask or refer if their knowledge on the topic is limited. One participant felt like

their audiologist was so caught up on trying to sell HAs that they failed to acknowledge a CI as an option; that participant had to instigate the referral themselves. These types of stories can be completely negated if audiologists refer when a client comes close to meeting the CI candidacy criteria, or no longer obtains satisfactory benefit from their HAs. Private clinic audiologists that work predominantly with HAs are often the first point of contact. They are also involved in rehabilitation post-implantation as many users are bimodal. Therefore, the significance of understanding the patient journey for CI users can help audiologists and other hearing professionals improve their level of care.

Another major finding discussed is the variety of sub-themes revealed by the participants. This highlights how each journey is unique and their experiences, although shared in some areas, are also extremely diverse and cannot be expressed as a collective. These results do highlight some of the common experiences but also acknowledge the need to listen to the individual experience. Patient-centred care has been shown in the nursing field to have a significant relationship with more positive outcomes for patients when compared to a less patient-centred/individualised approach (Bechel, Myers & Smith, 2000; Lauver, Ruff & Wells, 2004). This can be extrapolated and assumed that a patient-centred approach to hearing treatment will ultimately benefit the client.

Pre-implant expectations were also an important part of the patient's journey and their perceived outcomes and satisfaction. Almost half of the participants had high expectations for their CI before rehabilitation, and although these expectations were predominantly met, there were some common complaints with CIs. Since participants had a general consensus that music and the telephone was where the CI had the most difficulty, it is important for clinicians to understand the limitations of a CI. Understanding those limitations allows for more realistic expectations to be established in counselling methods before and during the rehabilitative process (Mäki-Torkko et al., 2015). The more professionals understand about

the patient journey for a CI user, the better they can tailor their care, ask the right questions and recommend the most appropriate treatment options.

In terms of social and funding implications, the present study discussed that most participants had a positive experience with their CI, and many became more involved with social activities and going out with others. There was an overwhelming consensus among the present study's participants supporting the positive outcomes for CI use and some had success with restoration of their previous life. However, there is a common barrier among private patients in achieving this outcome, and that barrier is cost. This is why the need for more funding for CIs within NZ is essential. Currently those who realistically can access a publicly funded CI are those who are still working. This leaves many retirees without means of treatment via a CI simply because they cannot afford it privately. Even amongst those working there is still a substantial waiting time for implantation; it can be up to two years (Bird, 2013). Although retirees do not often work, many are volunteers in their communities and still have significant potential to contribute as active members of society. Having retirees that can contribute more socially means they are more likely to be involved in their community and contribute to the economy e.g. eating dinner at a restaurant instead of at home. If an increase in public funding is not an option, the development/encouragement of more external funding options for those seeking CIs would be ideal. This could be achieved by raising more awareness about the difficulties in funding a CI which could help simulate and encourage more funding options through charitable organisations, trusts and community efforts. The cost-effectiveness of CIs has been explored. Foteff et al. (2016) evaluated the CI incremental cost-utility for Australian adults using the Markov model techniques and Quality Adjusted Life Year (QALY). This model allows for multiple treatment alternatives to be analysed while incorporating economic evaluations, costs and stated healthcare utilities. Their results concluded, when using a cost effectiveness threshold of $50,000 AUD per QALY, that

there was an incremental cost-utility ratio of $11,168AUD/QALY for CI treatment options (unilateral, bilateral and sequentially). They concluded that CIs were a cost-effective option when comparing to bilateral HAs. In Switzerland, Laske et al. (2019) evaluated age-related cost-effectiveness for unilateral CI in adults. Using the Markov model and a cost effectiveness threshold of $50,000 CHF (Swiss Franc) per QALY, they discovered that unilateral CI was cost-effective in women up to 91 years and 89 years for men. In comparison, bilateral HAs had a cost-effective age cut off at 87 for women and 85 for men. When using an increased threshold of $100,000 CHF which the researchers considered more realistic, they found unilateral CI was still cost-effective at 80 years for women and 78 years for men. They concluded that unilateral CI was a more cost-effective option for advanced ages when comparing it with bilateral HAs.

Study Limitations

Firstly, the present study might suffer from some selection bias due to the recruitment phase. This is inherent in any study where participants are invited to be involved. The information and consent form packages were distributed by the CI Clinic to participants that fit within our criteria. However, the participants who responded might have been more interested to participate because they had a more emotional experience (one which is more positive or negative). Although, there is no evidence to suggest that participants are more likely to sign up to a study if their experience is more extreme. However, there is evidence that more emotional experiences are involved with memory consolidation and memory retrieval (Tyng, Amin, Saad & Malik, 2017). More emotionally neutral stimuli are less likely to undergo the same level of memory coding and consolidation and are more likely to be forgotten (Hamann, 2001). So those who have had a more emotional experience might be more likely to share that experience as they are more likely to have consolidated that information. This poses a limitation in two ways: (1) that a certain population of participants

(ones who felt a more neutral experience) may be less likely to sign up and (2) that same population that might be less likely to participate could provide new or different experiences that therefore will not be recorded.

As is inherent to qualitative interviews, factors such as recall, memory, priming bias, and willingness to share information are factors that need to be considered in interpreting the results obtained. More emotional/intense experience helps with memory consolidation but there is evidence to suggest that human memory recall is not very accurate and lacks detail. Studies that assessed free recall using word lists have shown that human memory is fragile and unpredictable (Naim, Katkov, Romani, & Tsodyks, 2020). This means the present study might possess recall bias due to the natural limitations of human memory. Priming bias is a phenomenon where exposure to one stimulus influences the response to another stimulus (Weingarten et al., 2016). This was mitigated as much as possible in the interview structure. However, there were times where some participants needed encouragement to talk about the presented topics. Similarly, there were differences in how open participants were. Interviews ranged from 29 minutes to 1 hour and 26 minutes, with the average interview time of approximately 57 minutes. Participants who had shorter interviews were often more reluctant to share thoughts and feelings surrounding the topic. Although this could be a limitation, it also could be a part of that individual's personality and taking a blunt/objective approach is true to their experience.

Qualitative research in particular phenomenological studies do not require large sample sizes to sufficiently tackle research questions; they rely on reaching saturation. Saturation was reached for main themes. However, with the complexity of the patient journey, sub-themes show more variety and are unlikely to reach saturation with small sample sizes. The small sample size could suggest that the information presented in the present study could be difficult to extrapolate to the wider population. One of the major

findings in this research was how individualised the patient journey is; extrapolating the participants experiences to the wider community might not always be appropriate. Similarly, another limitation was that the demographics of the present study's sample population was limited. All participants were NZ European, and most fell within the retired age bracket. Although, without having demographic information of all privately funding CIs in NZ it would be difficult to assume that this sample is or is not indicative of the wider private CI population.

Because the present study only involved CI users who privately funded their treatment, the results may not be reflective of CI users in NZ who received their CI through the public system or others seeking a CI who cannot afford it. The participants in this study could be in a wealthier socio-economic bracket or be more socially involved to have achieved funding for their CI. However, one of the aims of this study was to determine the sources of private funding to help with suggestions for alternative funding methods because of the limited funding in NZ.

Time and travel constraints affected the ability to have more interviews. Several who were interested in participating were not available in the time windows offered for interviews in their home region. There were also those who were interested and then failed to arrange a time and meeting place, further reducing the number of interviews that could take place.

Future Research

Because of time limitations requiring the study to be completed within 12 months and the small private CI user population in NZ, a retrospective approach was taken. The retrospective framework comes with several limitations, primarily recall bias, that a longitudinal study would not endure. Interviewing participants at each stage during their journey (e.g. pre-CI, <3 months post and 12-18 months post switch on) would account for

any issues regarding recollection bias discussed earlier. The time points used in the example would give the best results based on information regarding progression of speech and QOL improvement post-switch on to gauge the feelings in each stage of progress with the CI. Before three months is where the most rapid improvement of speech perception scores is observed, but it can be a difficult time for users to adjust. By 12 months most CI users have plateaued with speech perception scores. The example time points are supported by Blamey et al. (2012) and Holden et al. (2013), discussed earlier in the literature review. Future research which executes a longitudinal design would be useful. The journey could be mapped more accurately and not have complications surrounding the validity of participants' recall of experience. While the participants are in each stage of the journey, it is possible they would share a more honest experience as their emotions and feelings could be more intense than during recollection. Modelling the journey as it takes place would provide crucial information that could support the findings of the present study and further develop our understanding of the journey and transition from HAs to CIs.

If future research has similar time restraints to the present study (<12 months) a prospective design, only interviewing pre-implantation, could be conducted. Research discovering the thoughts, feelings and experiences of individuals prior to receiving treatment would also help develop the patient journey. Further understanding of the thoughts and feelings before undergoing the CI rehabilitative process will be an important addition in providing more detail for the patient journey. Those who seek CI rehabilitative care and did not follow through could also be a useful area to explore. Discovering what barriers are preventing individuals from pursuing with treatment will be helpful in proposing ways to assist others with their rehabilitative journey.

A replication of the present study, using CI users with publicly funded treatment, could also be useful. This data could be used to compare findings to see similarities and/or

differences between the different demographics. It could provide more clarity for proposing an increase in public funding if the benefits experienced are largely the same.

Overall, there is an absence of research understanding the patient journey through the transition period from HAs to CIs. This study is the first to start developing that model and sharing the patient experience. Any research developing on the patient journey for those who have undergone rehabilitative treatment with CIs would be an important step forward in creating a more collective body of evidence to help clinicians provide better patient-centred care, and Governments in their distribution of funds in healthcare.

Conclusion

In conclusion, the majority of participants had positive outcomes in their journey from HAs to CI. This reflects how essential a CI can be for those experiencing a severe-to-profound HI and the positive impact it can have on their lives. The study supports the notion that those who privately funded their CI have similar outcomes to those who had a CI publicly funded. Although, comparative research has not been conducted within NZ. These findings highlighted the ongoing issues with limited public funding of CIs in NZ. There is a need for more public and/or alternative funding methods to increase CI accessibility.

The study's findings support the patient-centred care approach due to the individuality and diversity observed among participants. Hearing professionals' opinions are highly trusted and are an essential source of information along every stage in an individual's journey. Therefore, it is integral that hearing professionals keep up to date with current research to give their patients the best level of care possible.

References

Aimoni, C., Ciorba, A., Hatzopoulos, S., Ramacciotti, G., Mazzoli, M., Bianchini, C., . . . Skarżyński, P. H. (2016). Cochlear implants in subjects over age 65: quality of life and audiological outcomes. *Medical science monitor: international medical journal of experimental and clinical research, 22*, 3035.

Anderson, I., Baumgartner, W.-D., Böheim, K., Nahler, A., Arnolder, C., & D'Haese, P. (2006). Telephone use: What benefit do cochlear implant users receive? *International Journal of Audiology, 45*(8), 446-453. doi:10.1080/14992020600690969

Athalye, S., Mulla, I., & Archbold, S. (2014). The experiences of adults assessed for cochlear implantation who did not proceed. *Cochlear implants international, 15(6),* 301-311.

Baltes, P. B., & Lindenberger, U. (1997). Emergence of a powerful connection between sensory and cognitive functions across the adult life span: a new window to the study of cognitive aging?. *Psychology and aging*, *12*(1), 12.

Bechel, D. L., Myers, W. A., & Smith, D. G. (2000). Does patient-centered care pay off? *TheJoint Commission journal on quality improvement, 26*(7), 400-409.

Bernstein, J. G. W., Summers, V., Grassi, E., & Grant, K. W. (2013). Auditory models of suprathreshold distortion and speech intelligibility in persons with impaired hearing. *Journal of the American Academy of Audiology*, *24*(4), 307-328. doi:10.3766/jaaa.24.4.6

Berrettini, S., Baggiani, A., Bruschini, L., Cassandro, E., Cuda, D., Filipo, R., ... & Forli, F. (2011). Systematic review of the literature on the clinical effectiveness of the cochlear implant procedure in adult patients. *Acta Otorhinolaryngologica Italica*, *31*(5), 299.

Bierbaum, M., McMahon, C. M., Hughes, S., Boisvert, I., Lau, A. Y. S., Braithwaite, J., & Rapport, F. (2020). Barriers and Facilitators to Cochlear Implant Uptake in Australia and the United Kingdom. *Ear and Hearing, 41*(2), 374-385. doi:10.1097/AUD.0000000000000762

Bille, M., & Parving, A. (2003). Expectations about hearing aids: demographic and audiological predictors: Expectativas acerca de los auxiliares auditivos: predictores demográficos y audiológicos. *International Journal of Audiology, 42*(8), 481-488. doi:10.3109/14992020309081518

Bird, P. (2013). Cochlear implants--there's still a queue. *The New Zealand Medical Journal*, 126(1375), 6.

Blamey, P., Artieres, F., Başkent, D., Bergeron, F., Beynon, A., Burke, E., . . . Lazard, D. S. (2012). Factors Affecting Auditory Performance of Postlinguistically Deaf Adults Using Cochlear Implants: An Update with 2251 Patients. *Audiology and Neurotology, 18*(1), 36-47.

Bor, S., Souza, P., & Wright, R. (2008). Multichannel compression: Effects of reduced spectral contrast on vowel identification. *Journal of Speech, Language, and Hearing Research*.

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *The Annals of Family Medicine, 2*(6), 576-582.

Bruns, L., Mürbe, D., & Hahne, A. (2016). Understanding music with cochlear implants. In (Vol. 6, pp. 32026). England: Nature Publishing Group.

Budenz, C. L., Cosetti, M. K., Coelho, D. H., Birenbaum, B., Babb, J., Waltzman, S. B., & Roehm, P. C. (2011). The Effects of Cochlear Implantation on Speech Perception in

Older Adults. *Journal of the American Geriatrics Society, 59*(3), 446-453. doi:10.1111/j.1532-5415.2010.03310.x

Byrne, D., Parkinson, A., & Newall, P. (1990). Hearing aid gain and frequency response requirements for the severely/profoundly hearing impaired. *Ear and hearing, 11*(1), 40-49.

Carlson, M. L., Breen, J. T., Driscoll, C. L., Link, M. J., Neff, B. A., Gifford, R. H., & Beatty, C. W. (2012). Cochlear implantation in patients with neurofibromatosis type 2: variables affecting auditory performance. *Otology & Neurotology, 33*(5), 853-862.

Chatelin, V., Kim, E. J., Driscoll, C., Larky, J., Polite, C., Price, L., & Lalwani, A. K. (2004). Cochlear implant outcomes in the elderly. *Otology & Neurotology, 25*(3), 298-301.

Ching, T. Y. C., Incerti, P., & Hill, M. (2004). Binaural Benefits for Adults Who Use Hearing Aids and Cochlear Implants in Opposite Ears. *Ear and Hearing, 25*(1), 9-21. doi:10.1097/01.AUD.0000111261.84611.C8

Chisolm, T. H., Johnson, C. E., Danhauer, J. L., Portz, L. J., Abrams, H. B., Lesner, S., ... & Newman, C. W. (2007). A systematic review of health-related quality of life and hearing aids: final report of the American Academy of Audiology Task Force on the Health-Related Quality of Life Benefits of Amplification in Adults. *Journal of the American Academy of Audiology, 18*(2), 151-183.

Chundu, S., & Stephens, N. (2013). Patients' involvement in choosing a cochlear implant. *Cochlear Implants International, 14*(3), 165-168. doi:10.1179/1754762812Y.0000000010

Cohen, S. M., Labadie, R. F., Dietrich, M. S., & Haynes, D. S. (2004). Quality of life in hearing-impaired adults: the role of cochlear implants and hearing aids. *Otolaryngology—Head and Neck Surgery, 131*(4), 413-422.

Cosh, S., Carriere, I., Daien, V., Amieva, H., Tzourio, C., Delcourt, C., ... & Sense-Cog Consortium. (2018). The relationship between hearing loss in older adults and depression over 12 years: Findings from the Three-City prospective cohort study. *International journal of geriatric psychiatry*, *33*(12), 1654-1661.

Cox, R. M., & Alexander, G. C. (2000). Expectations about hearing aids and their relationship to fitting outcome. *Journal of the American Academy of Audiology*, *11*(7), 368.

Damen, G. W., Beynon, A. J., Krabbe, P. F., Mulder, J. J., & Mylanus, E. A. (2007). Cochlear implantation and quality of life in postlingually deaf adults: long-term follow-up. *Otolaryngology—Head and Neck Surgery, 136(4)*, 597-604.

Dawes, P., Emsley, R., Cruickshanks, K. J., Moore, D. R., Fortnum, H., Edmondson-Jones, M., ... & Munro, K. J. (2015). Hearing loss and cognition: the role of hearing AIDS, social isolation and depression. *PloS one*, *10*(3).

De Jong-Gierveld, J., & Kamphuls, F. (1985). The development of a Rasch-type loneliness scale. *Applied psychological measurement*, *9*(3), 289-299.

Dillon, H. (2012). *Hearing Aids, Second edition*. Sydney, Australia: Boomerang Press.

Domagała-Zyśk, E. (2019). Older Persons With Subjectively Assessed Hearing Problems in Poland: Quality of Life and Coping Strategies. *American annals of the deaf*, *164*(3), 381-394.

Dorman, M. F., Cook, S., Spahr, A., Zhang, T., Loiselle, L., Schramm, D., . . . Gifford, R. (2015). Factors constraining the benefit to speech understanding of combining information from low-frequency hearing and a cochlear implant. *Hearing Research*, *322*, 107-111.

Drennan, W. R., Oleson, J. J., Gfeller, K., Crosson, J., Driscoll, V. D., Won, J. H., . . . Rubinstein, J. T. (2015). *Clinical evaluation of music perception, appraisal and experience in cochlear implant users*. England: Informa Healthcare. doi:10.3109/14992027.2014.948219

Dunn, C. C., Noble, W., Tyler, R. S., Kordus, M., Gantz, B. J., & Ji, H. (2010). Bilateral and unilateral cochlear implant users compared on speech perception in noise. *Ear and Hearing, 31(2),* 296.

Dunn, C. C., Tyler, R. S., & Witt, S. A. (2005). Benefit of wearing a hearing aid on the unimplanted ear in adult users of a cochlear implant. *Journal of Speech, Language, and Hearing Research. 48(3),* 668-680. doi.org/10.1044/1092-4388(2005/046)

Eshraghi, A. A., Nazarian, R., Telischi, F. F., Rajguru, S. M., Truy, E., & Gupta, C. (2012). The cochlear implant: historical aspects and future prospects. *The Anatomical Record: Advances in Integrative Anatomy and Evolutionary Biology, 295*(11), 1967-1980.

Ferguson, M. A., Kitterick, P. T., Chong, L. Y., Edmondson-Jones, M., Barker, F., & Hoare, D. J. (2017). Hearing aids for mild to moderate hearing loss in adults. *Cochrane Database of Systematic Reviews*, (9).

Finlay, L., & Molano-Fisher, P. (2008). 'Transforming'self and world: a phenomenological study of a changing lifeworld following a cochlear implant. *Medicine, Health Care and Philosophy, 11(3*), 255-267.

Firszt, J. B., Holden, L. K., Reeder, R. M., Cowdrey, L., & King, S. (2012). Cochlear implantation in adults with asymmetric hearing loss. *Ear and Hearing, 33(4)*, 521.

Firszt, J. B., Reeder, R. M., & Skinner, M. W. (2008). Restoring hearing symmetry with two cochlear implants or one cochlear implant and a contralateral hearing aid. *Journal of Rehabilitation Research and Development.45(5),* 749-768.

Foteff, C., Kennedy, S., Milton, A. H., Deger, M., Payk, F., & Sanderson, G. (2016). Cost–Utility Analysis of Cochlear Implantation in Australian Adults. *Otology & Neurotology, 37*(5), 454-461. doi:10.1097/MAO.0000000000000999

Foss, C. (2011). Elders and patient participation revisited–a discourse analytic approach to older persons' reflections on patient participation. *Journal of Clinical Nursing*, *20*(13-14), 2014-2022.

Gates, G. A., & Mills, J. H. (2005). Presbycusis. *The Lancet, 366*(9491), 1111-1120. doi:10.1016/S0140-6736(05)67423-5

Gaylor, J. M., Raman, G., Chung, M., Lee, J., Rao, M., Lau, J., & Poe, D. S. (2013). Cochlear implantation in adults: a systematic review and meta-analysis. *JAMA Otolaryngology–Head & Neck Surgery, 139*(3), 265-272.

Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2004). The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing, 33(4),* 422-426.

Gifford, R. H., Dorman, M. F., McKarns, S. A., & Spahr, A. J. (2007). Combined electric and contralateral acoustic hearing: Word and sentence recognition with bimodal hearing. *Journal of Speech, Language, and Hearing Research*.

Gifford, R. H., Shallop, J. K., & Peterson, A. M. (2008). Speech recognition materials and ceiling effects: Considerations for cochlear implant programs. *Audiology and Neurotology, 13*(3), 193-205.

Gomez, R. G., & Madey, S. F. (2001). Coping-With-Hearing-Loss Model for Older Adults. *The Journals of Gerontology: Series B, 56*(4), P223-P225. doi:10.1093/geronb/56.4.P223

Goodman, A. (1965). Reference zero levels for pure-tone audiometer. *Asha*, *7*(262), 1.

Green, K. M. J., Bhatt, Y. M., Mawman, D. J., O'Driscoll, M. P., Saeed, S. R., Ramsden, R. T., & Green, M. W. (2007). Predictors of audiological outcome following cochlear implantation in adults. *Cochlear Implants International, 8*(1), 1-11. doi:10.1002/cii.326

Guitar, K., Giles, E., Raymond, B., & Welch, D. (2013). Health effects of cochlear implants. *The New Zealand medical journal*, *126*(1375), 9.

Gullacksen, A.-C., & Lidbeck, J. (2004). The life adjustment process in chronic pain: psychosocial assessment and clinical implications. *Pain Research and Management, 9(3),* 145-153.

Gullacksen, A.-C. (2017). Examples of the Journey Through Hearing Loss. In V. Manchaiah & B. Danermark (Eds.), *The Experience of Hearing Loss* (pp. 145-156). Routledge.

Gunn, R. G. (2010). Adult cochlear implants in New Zealand--a chronic funding issue. *The New Zealand medical journal, 123*(1321), 9.

Hallberg, L. R. M., & Ringdahl, A. (2004). Living with cochlear implants: experiences of 17 adult patients in Sweden. *International journal of audiology, 43(2),* 115-121.

Hällgren, M., Larsby, B., Lyxell, B., & Arlinger, S. (2005). Speech understanding in quiet and noise, with and without hearing aids: Comprensión del lenguaje en silencio y con ruido, con y sin auxiliares auditivos. *International Journal of Audiology*, *44*(10), 574-583.

Hamann, S. (2001). Cognitive and neural mechanisms of emotional memory. *Trends in cognitive sciences, 5*(9), 394-400.

Häußler, S. M., Knopke, S., Wiltner, P., Ketterer, M., Gräbel, S., & Olze, H. (2019). Long-term Benefit of Unilateral Cochlear Implantation on Quality of Life and Speech Perception in Bilaterally Deafened Patients. *Otology & Neurotology, 40*(4), e430-e440. doi:10.1097/MAO.0000000000002008

Heo, J.-H., Lee, J.-H., & Lee, W.-S. (2013). Bimodal benefits on objective and subjective outcomes for adult cochlear implant users. *Korean journal of audiology, 17(2),* 65-73. doi:10.7874/kja.2013.17.2.65

Hinderink, J. B., Krabbe, P. F., & Van Den Broek, P. (2000). Development and application of a health-related quality-of-life instrument for adults with cochlear implants: the Nijmegen cochlear implant questionnaire. *Otolaryngology-Head and Neck Surgery, 123(6),* 756-765.

Hogan, A. (1997). Implant outcomes: towards a mixed methodology for evaluating the efficacy of adult cochlear implant programmes. *Disability and rehabilitation, 19(6),* 235-243.

Hoit, J. D., & Weismer, G. (2016). *Foundations of Speech and Hearing: Anatomy and Physiology* (1st ed.). San Diego: Plural Publishing, Inc.

Holden, L. K., Finley, C. C., Firszt, J. B., Holden, T. A., Brenner, C., Potts, L. G., ... & Skinner, M. W. (2013). Factors affecting open-set word recognition in adults with cochlear implants. *Ear and hearing, 34(3),* 342.

Holman, J. A., Drummond, A., Hughes, S. E., & Naylor, G. (2019). Hearing impairment and daily-life fatigue: a qualitative study. *International Journal of Audiology, 58*(7), 408-416. doi:10.1080/14992027.2019.1597284

House, W. F., & Urban, J. (1973). Long term results of electrode implantation and electronic stimulation of the cochlea in man. *Annals of Otology, Rhinology & Laryngology*, *82*(4), 504-517.

Ida Institute. (2019) *Patient Journey.* Retrieved from https://idainstitute.com/tools/self_development/get_started/patient_journey/?tx_idatoolbox_toolboxpagelist%5Bcontroller%5D=Toolbox&cHash=0a7538ad57f431f4a15b33459c2589dc

Ida Institute. (2020) *Understanding A Patient Journey* Retrieved from https://idainstitute.com/tools/a_patient_journey/understanding_a_patient_journey/

Ishine, M., Okumiya, K., & Matsubayashi, K. (2007). A close association between hearing impairment and activities of daily living, depression, and quality of life in community-dwelling older people in Japan. *Journal of the American Geriatrics Society*, *55*(2), 316-317.

Jerger, J., Chmiel, R., Wilson, N., & Luchi, R. (1995). Hearing impairment in older adults: new concepts. *Journal of the American Geriatrics Society*, *43*(8), 928-935.

Jorgensen, L. E., Benson, E. A., & McCreery, R. W. (2018). Conventional Amplification for Children and Adults with Severe-to-Profound Hearing Loss. *Seminars in hearing*, *39*(4), 364-376. doi:10.1055/s-0038-1670699

Kahana, E., Kelley-Moore, J., & Kahana, B. (2012). Proactive aging: A longitudinal study of stress, resources, agency, and well-being in late life. *Aging & Mental Health*, *16*(4), 438-451.

Kahana, B., Yu, J., Kahana, E., & Langendoerfer, K. B. (2018). Whose advocacy counts in shaping elderly patients' satisfaction with physicians' care and communication? *Clinical interventions in aging*, *13*, 1161.

Kamil, R. J., & Lin, F. R. (2015). The effects of hearing impairment in older adults on communication partners: a systematic review. *Journal of the American Academy of Audiology*, *26*(2), 155-182. doi:10.3766/jaaa.26.2.6

Klop, W. M. C., Briaire, J. J., Stiggelbout, A. M., & Frijns, J. H. (2007). Cochlear implant outcomes and quality of life in adults with prelingual deafness. *The Laryngoscope, 117(11)*, 1982-1987.

Kuk, F., Lau, C. C., Korhonen, P., & Crose, B. (2015). Speech intelligibility benefits of hearing aids at various input levels. *Journal of the American Academy of Audiology*, *26*(3), 275-288.

Kutz Jr, J. W., Lee, K. H., Isaacson, B., Booth, T. N., Sweeney, M. H., & Roland, P. S. (2011). Cochlear implantation in children with cochlear nerve absence or deficiency. *Otology & Neurotology*, *32*(6), 956-961.

Laplante-Lévesque, A., Hickson, L., & Worrall, L. (2010). Factors influencing rehabilitation decisions of adults with acquired hearing impairment. *International Journal of Audiology*, *49*(7), 497-507. doi:10.3109/14992021003645902

Lauver, D. R., Gross, J., Ruff, C., & Wells, T. J. (2004). Patient-centered interventions: implications for incontinence. *Nursing Research, 53*(6S), S30-S35.

Laske, R. D., Dreyfuss, M., Stulman, A., Veraguth, D., Huber, A. M., & Röösli, C. (2019). Age Dependent Cost-Effectiveness of Cochlear Implantation in Adults. Is There an Age Related Cut-off? *Otology & Neurotology*, *40*(7), 892-899. doi:10.1097/MAO.0000000000002275

Lazard, D. S., Vincent, C., Venail, F., Van de Heyning, P., Truy, E., Sterkers, O., ... & Mawman, D. (2012). Pre-, per-and postoperative factors affecting performance of

postlinguistically deaf adults using cochlear implants: a new conceptual model over time. *PloS one*, *7*(11).

Levesque, C. S., Williams, G. C., Elliot, D., Pickering, M. A., Bodenhamer, B., & Finley, P. J. (2007). Validating the theoretical structure of the Treatment Self-Regulation Questionnaire (TSRQ) across three different health behaviors. *Health education research*, *22*(5), 691-702.

Li, C.-M., Zhang, X., Hoffman, H. J., Cotch, M. F., Themann, C. L., & Wilson, M. R. (2014). Hearing impairment associated with depression in US adults, National Health and Nutrition Examination Survey 2005-2010. *JAMA Otolaryngology–Head & Neck Surgery*, *140*(4), 293-302.

Limb, C. J., and Roy, A. T. (2014). Technological, biological, and acoustical constraints to music perception in cochlear implant users. *Hear. Res. 308,* 13–26. doi: 10.1016/j.heares.2013.04.009

Lin, F. R., Yaffe, K., Xia, J., Xue, Q.-L., Harris, T. B., Purchase-Helzner, E., . . . Simonsick, E. M. (2013). Hearing loss and cognitive decline in older adults. *JAMA internal medicine*, *173(4),* 293-299.

Lindenberger, U., & Baltes, P. B. (1994). Sensory functioning and intelligence in old age: a strong connection. *Psychology and aging*, *9*(3), 339.

Looi, V., Bluett, C., & Boisvert, I. (2017). Referral rates of postlingually deafened adult hearing aid users for a cochlear implant candidacy assessment. *International journal of audiology*, *56*(12), 919-925.

Looi, V., Gfeller, K., & Driscoll, V. D. (2012). Music Appreciation and Training for Cochlear Implant Recipients: A Review. *Seminars in hearing*, *33*(4), 307-334. doi:10.1055/s-0032-1329222\

Looi, V., Mackenzie, M., & Bird, P. (2011). Quality-of-life outcomes for adult cochlear implant recipients in New Zealand. *New Zealand medical journal, 124*(1340), 21-34.

Looi, V., & She, J. (2010). Music perception of cochlear implant users: a questionnaire, and its implications for a music training program. *International journal of audiology, 49(2),* 116-128.

Lupo, J. E., Biever, A., & Kelsall, D. C. (2019). Comprehensive hearing aid assessment in adults with bilateral severe-profound sensorineural hearing loss who present for Cochlear implant evaluation. *American Journal of Otolaryngology,* 102300. doi:10.1016/j.amjoto.2019.102300

Magnusson, L., Claesson, A., Persson, M., & Tengstrand, T. (2013). Speech recognition in noise using bilateral open-fit hearing aids: The limited benefit of directional microphones and noise reduction. *International Journal of Audiology, 52*(1), 29-36. doi:10.3109/14992027.2012.707335

Mahon, J. L., Bourne, R. B., Rorabeck, C. H., Feeny, D. H., Stitt, L., & Webster-Bogaert, S. (2002). Health-related quality of life and mobility of patients awaiting elective total hip arthroplasty: a prospective study. *CMAJ : Canadian Medical Association journal, 167*(10), 1115-1121.

Mäki-Torkko, E. M., Vestergren, S., Harder, H., & Lyxell, B. (2015). From isolation and dependence to autonomy – expectations before and experiences after cochlear implantation in adult cochlear implant users and their significant others. *Disability and rehabilitation, 37*(6), 541-547. doi:10.3109/09638288.2014.935490

Manchaiah, V. K., & Stephens, D. (2011). The patient journey: living with hearing impairment. *J Acad Rehabil Audiol, 44,* 29-40.

Manchaiah, V. K. C., & Stephens, D. (2013). Perspectives on defining 'hearing loss' and its consequences. *Hearing, Balance and Communication, 11*(1), 6-16. doi:10.3109/21695717.2012.756624

Manchaiah, V. K. C., Stephens, D., & Meredith, R. (2011). The patient journey of adults with hearing impairment: The patients' views. *Clinical Otolaryngology*, 36(3), 227-234. doi:10.1111/j.1749-4486.2011.02320.x

Manchaiah, V., Rönnberg, J., Andersson, G., & Lunner, T. (2014). Use of the 'patient journey'model in the internet-based pre-fitting counseling of a person with hearing disability: Lessons from a failed clinical trial. *BMC Ear, Nose and Throat Disorders, 14*(1), 3.

Mathers, C., Smith, A., & Concha, M. (2000). Global burden of hearing loss in the year 2000. *Global burden of Disease*, *18*(4), 1-30.

Maxwell, A., Özmen, M., Iezzi, A., & Richardson, J. (2016). Deriving population norms for the AQoL-6D and AQoL-8D multi-attribute utility instruments from web-based data. *Quality of life research*, 25(12), 3209-3219.

McCreery, R. W., Venediktov, R. A., Coleman, J. J., & Leech, H. M. (2012). An evidence-based systematic review of directional microphones and digital noise reduction hearing aids in school-age children with hearing loss. *American journal of audiology, 21*(2), 295-312. doi:10.1044/1059-0889(2012/12-0014)

McWhinnie, J. R. (1979). Disability indicators for measuring well-being (OECD social indicators development program, special studies no. 5).

Mick, P., Kawachi, I., & Lin, F. R. (2014). The association between hearing loss and social isolation in older adults. *Otolaryngology–Head and Neck Surgery*, *150*(3), 378-384.

Mick, P. T., & Lin, F. R. (2013). Social isolation and hearing loss in the elderly. *Otolaryngology—Head and Neck Surgery*, *149*(2_suppl), P110-P110.

Minichiello, V., Aroni, R., & Minichiello, V. (1990). *In-depth interviewing: Researching people:* Longman Cheshire.

Ministry of Health. (2015). *Cochlear Implants*. Retrieved January 05, 2020, from https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/hearing-and-vision-services/hearing-services/cochlear-implants

Montes, F., Peñaranda, A., Correa, S., Peñaranda, D., García, J.-M., Aparicio, M. L., . . . Castillo, M. (2017). Cochlear Implants Versus Hearing Aids in a Middle-Income Country: Costs, Productivity, and Quality of Life. *Otology & Neurotology, 38*(5), e26-e33. doi:10.1097/MAO.0000000000001393

Mosnier, I., Bebear, J. P., Marx, M., Fraysse, B., Truy, E., Lina-Granade, G., ... & Godey, B. (2014). Predictive factors of cochlear implant outcomes in the elderly. *Audiology and Neurotology*, *19*(Suppl. 1), 15-20.

Mudry, A., & Mills, M. (2013). The early history of the cochlear implant: a retrospective. *JAMA Otolaryngology–Head & Neck Surgery*, *139*(5), 446-453.

Mulrow, C. D., Tuley, M. R., & Aguilar, C. (1992). Sustained benefits of hearing aids. *Journal of Speech, Language, and Hearing Research*, *35*(6), 1402-1405.

National Institute on Deafness and Other Communication Disorders. (2016). *Cochlear Implants.* Retrieved from https://www.nidcd.nih.gov/health/cochlear-implants

Naim, M., Katkov, M., Romani, S., & Tsodyks, M. (2020). Fundamental law of memory recall. *Physical Review Letters, 124*(1), 018101.

Northern Cochlear Implant Programme, (2020). *Health Professionals*. Retrieved from https://www.ncip.org.nz/health-professionals

Nsamba, C. (1972). A comparative study of the aetiology of vertigo in the African. *The Journal of Laryngology & Otology*, *86*(9), 917-925.

Organisation mondiale de la santé, World Health Organization, & World Health Organization Staff. (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.

Pathak, V., Jena, B., & Kalra, S. (2013). Qualitative research. P*erspectives in clinical research, 4(3)*, 192-192. doi:10.4103/2229-3485.115389

Plassman, B. L., Williams, J. W., Burke, J. R., Holsinger, T., & Benjamin, S. (2010). Systematic review: factors associated with risk for and possible prevention of cognitive decline in later life. *Annals of internal medicine*, *153*(3), 182-193.

Pope, C., & Mays, N. (2006). Qualitative methods in health research. *Qualitative research in health care*, *3*, 1-11.

Potts, L. G., Skinner, M. W., Litovsky, R. A., Strube, M. J., & Kuk, F. (2009). Recognition and localization of speech by adult cochlear implant recipients wearing a digital hearing aid in the nonimplanted ear (bimodal hearing). *Journal of the American Academy of Audiology*, *20(6)*, 353-373.

Prochaska, J. O., & DiClemente, C. C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: theory, research & practice*, *19*(3), 276.

Pronk, M., Deeg, D. J. H., & Kramer, S. E. (2013). Hearing Status in Older Persons: A Significant Determinant of Depression and Loneliness? Results From the Longitudinal Aging Study Amsterdam. *American journal of audiology, 22*(2), 316-320. doi:10.1044/1059-0889(2013/12-0069)

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement, 1*(3), 385-401.

Rembar, S., Lind, O., Arnesen, H., & Helvik, A. S. (2009). Effects of cochlear implants: a qualitative study. Cochlear Implants International, 10(4), 179-197. doi:10.1002/cii.402

Ridgway, J., Hickson, L., & Lind, C. (2015). Autonomous motivation is associated with hearing aid adoption. *International Journal of Audiology, 54*(7), 476-484. doi:10.3109/14992027.2015.1007213

Saunders, G. H., Lewis, M. S., & Forsline, A. (2009). Expectations, Prefitting Counseling, and Hearing Aid Outcome. *Journal of the American Academy of Audiology, 20*(5), 320-334. doi:10.3766/jaaa.20.5.6

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., . . . Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity, 52*(4), 1893-1907.

Saito, H., Nishiwaki, Y., Michikawa, T., Kikuchi, Y., Mizutari, K., Takebayashi, T., & Ogawa, K. (2010). Hearing handicap predicts the development of depressive symptoms after 3 years in older community-dwelling Japanese. *Journal of the American Geriatrics Society, 58*(1), 93-97.

Sladen, D. P., & Zappler, A. (2015). Older and younger adult cochlear implant users: speech recognition in quiet and noise, quality of life, and music perception. *American journal of audiology, 24*(1), 31-39. doi:10.1044/2014_AJA-13-0066

Smith, S. M., & Kampfe, C. M. (1997). Interpersonal Relationship Implications of Hearing Loss in Persons Who Are Older. *The Journal of Rehabilitation, 63*(2), 15.

Smulders, Y. E., van Zon, A., Stegeman, I., Rinia, A. B., Van Zanten, G. A., Stokroos, R. J., . . . Grolman, W. (2016). Comparison of Bilateral and Unilateral Cochlear Implantation in Adults: A Randomized Clinical Trial. *JAMA otolaryngology head & neck surgery 142(3),* 249.

Sorkin, D. L. (2013). Cochlear implantation in the world's largest medical device market: Utilization and awareness of cochlear implants in the United States. *Cochlear Implants International: Access to Cochlear Implantation, 14*(sup1), S12-S14. doi:10.1179/1467010013Z.00000000076

Southern Cochlear Implant Programme. (2018). *Referral and assessment.* Retrieved from https://scip.co.nz/patient-information/treatment-for-adults/referral-and-assessment-adults/

Stark, P., & Hickson, L. (2004). Outcomes of hearing aid fitting for older people with hearing impairment and their significant others. *International Journal of Audiology, 43*(7), 390-398. doi:10.1080/14992020400050050

Strawbridge, W. J., Wallhagen, M. I., Shema, S. J., & Kaplan, G. A. (2000). Negative Consequences of Hearing Impairment in Old Age: A Longitudinal Analysis. *The Gerontologist, 40*(3), 320-326. doi:10.1093/geront/40.3.320

Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: prospects and challenges for health psychology. *Health psychology, 23(2),* 119.

Svinndal, E. V., Jensen, C., & Rise, M. B. (2020). Working life trajectories with hearing impairment. *Disability and rehabilitation, 42*(2), 190-200. doi:10.1080/09638288.2018.1495273

Tyng, C. M., Amin, H. U., Saad, M. N. M., & Malik, A. S. (2017). The Influences of Emotion on Learning and Memory. *Frontiers in psychology, 8*, 1454-1454. doi:10.3389/fpsyg.2017.01454

Van Loon, M. C., Smits, C., Smit, C. F., Hensen, E. F., & Merkus, P. (2017). Cochlear implantation in adults with asymmetric hearing loss: benefits of bimodal stimulation. *Otology & Neurotology*, *38*(6), e100-e106.

van Til, M. J., Kramer, S. E., Anema, J. R., & Goverts, S. T. T. (2016). Working with hearing impairment: an integrated approach. *Nederlands tijdschrift voor geneeskunde, 160*, A9575.

Vos, T., Allen, C., Arora, M., Barber, R. M., Bhutta, Z. A., Brown, A., ... & Coggeshall, M. (2016). Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*, *388*(10053), 1545-1602.

Wallhagen, M. I., Strawbridge, W. J., & Kaplan, G. (1996). 6-year impact of hearing impairment on psychosocial and physiologic functioning.

Wanna, G. B., Noble, J. H., Carlson, M. L., Gifford, R. H., Dietrich, M. S., Haynes, D. S., ... & Labadie, R. F. (2014). Impact of electrode design and surgical approach on scalar location and cochlear implant outcomes. *The Laryngoscope*, *124*(S6), S1-S7.

Wanna, G. B., Noble, J. H., Gifford, R. H., Dietrich, M. S., Sweeney, A. D., Zhang, D., . . . Labadie, R. F. (2015). Impact of Intrascalar Electrode Location, Electrode Type, and Angular Insertion Depth on Residual Hearing in Cochlear Implant Patients: Preliminary Results. *Otology & Neurotology, 36*(8), 1343-1348.

Weingarten, E., Chen, Q., McAdams, M., Yi, J., Hepler, J., & Albarracín, D. (2016). From primed concepts to action: A meta-analysis of the behavioral effects of incidentally presented words. *Psychological Bulletin, 142*(5), 472.

Weinstein, B. E., & Ventry, I. M. (1982). Hearing impairment and social isolation in the elderly. *Journal of Speech, Language, and Hearing Research, 25*(4), 593-599.

Wahl, H.-W., & Heyl, V. (2003). Connections between vision, hearing, and cognitive function in old age. *Generations, 27*(1), 39-45.

Williams, L. (2019). Untreated severe-to-profound hearing loss and the cochlear implant situation: how policy and practice are disabling New Zealand society. *The New Zealand medical journal, 132*(1505), 73-78.

Williamson, R. A., Pytynia, K., Oghalai, J. S., & Vrabec, J. T. (2009). Auditory performance after cochlear implantation in late septuagenarians and octogenarians. *Otology & neurotology: official publication of the American Otological Society, American Neurotology Society [and] European Academy of Otology and Neurotology*, *30*(7), 916.

World Health Organisation. (2019, March 20). *Deafness and hearing loss.* Retrieved from https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss

World Health Organisation. (2018). *WHO Global Estimates on Prevalence of Hearing Loss* [PowerPoint slides]. Retrieved from. https://www.who.int/deafness/Global-estimates-on-prevalence-of-hearing-loss-for-website.pptx?ua=1

World Health Organisation. (2020). *WHOQOL: Measuring Quality of Life.* Retrieved from https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

World Health Organization, & World Health Organization Staff. (2001). *International classification of functioning, disability and health: ICF*. World Health Organization.

Wu, Y.-H., Stangl, E., Chipara, O., Hasan, S. S., DeVries, S., & Oleson, J. (2019). Efficacy and Effectiveness of Advanced Hearing Aid Directional and Noise Reduction Technologies for Older Adults With Mild to Moderate Hearing Loss. *Ear and Hearing*, *40*(4), 805-822. doi:10.1097/AUD.0000000000000672

Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric depression screening scale: a preliminary report. *Journal of psychiatric research*, *17*(1), 37-49.

Zhang, T., Dorman, M. F., & Spahr, A. J. (2010). Information from the voice fundamental frequency (F0) region accounts for the majority of the benefit when acoustic stimulation is added to electric stimulation. *Ear and Hearing, 31*(1), 63.

Appendix A

Ethics Approval Letter

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE
Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2019/03/LR

28 March 2019

Natasha De Jongh
Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Natasha

Thank you for submitting your low risk application to the Human Ethics Committee for the research proposal titled "The Patient Journey: From Hearing Aids to Cochlear Implants".

I am pleased to advise that this application has been reviewed and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 21st March 2019.

With best wishes for your project.

Yours sincerely

pp. R. Robinson

Professor Adrian Sawyer
Deputy Chair, Human Ethics Committee

Appendix B

Ethics Amendment Approval

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Rebecca Robinson
Telephone: +64 03 369 4588, Extn 94588
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2019/03/LR Amendment 1

8 April 2019

Natasha De Jongh
Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Natasha

Thank you for your request for an amendment to your research proposal "The Patient Journey: From Hearing Aids to Cochlear Implants" as outlined in your emails dated 1st and 3rd April 2019.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Yours sincerely

Dr Dean Sutherland
Chair, Human Ethics Committee

Appendix C

Māori Consultation Approval

Ngāi Tahu Research Centre

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Thursday 14 March 2019

Tēnā koe Rebecca Kelly

RE: The Patient Journey: From hearing aids to cochlear implants

This letter is on behalf of the Ngāi Tahu Research Centre (NTRC). They have considered your proposal and acknowledge it is a worthwhile and interesting project and you are clear about how you ought to take participants' (cultural) needs into account if and when applicable.

Given the scope of your project, no issues have been identified and further consultation with Māori is not required.

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement.

It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

The Ngāi Tahu Research Centre would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Ngā mihi whakawhetai ki a koe

Henrietta Carroll (on behalf of the NTRC)

Kaiarāhi Maori Research
Research & Innovation | Te Rōpū Rangahau
University of Canterbury | Te Whare Wānanga o Waitaha
Phone +64 3 369 0143, Private Bag 4800, Christchurch | Ōtautahi
henrietta.latimer@canterbury.ac.nz
http://www.research.canterbury.ac.nz

Appendix D

Participant Information Sheet

Department of Communication Disorders
Telephone: +64 3 369 4519
Email: natasha.dejongh@pg.canterbury.ac.nz
Date: 1 February 2019
HEC Ref: 2019/03/LR

The Patient Journey: From Hearing Aids to Cochlear Implants: A Retrospective Study
Information Sheet for study participants

My name is Natasha de Jongh, and I am a final year Masters of Audiology Student at the University of Canterbury. As part of my degree, I am doing a research study to look at a person's 'journey' or transition from hearing aids (HAs) to cochlear implants (CIs). Having a better understanding of this journey and transition will enable the audiologist and CI team provide more individualised care that better meets the need of the individual, as well as empowers the adult to be a more active participant in whole process.

We are focusing specifically on adults who have received a CI in NZ privately and are between 6 to 24 months post switch on. As the funding for public CIs is NZ is very limited, many adults who could benefit from a CI are not able to access one, and one of the secondary aims of this study is to determine potential sources of funding to help other adults who need a CI access one, as well as provide data that may encourage the NZ Ministry of Health to increase the funding allocated for adult CIs.

You have been approached to take part in this study because you elected to proceed with a cochlear implant on a privately funded basis. We are asking The Southern Cochlear Implant Program (SCIP) to pass on the information about this study to adults who have received a CI privately between 6 and 24 months post switch on.

If you choose to take part in this study, we would need you to participate in a single 1-hour interview, which will be audio-taped.
These interviews will be held at a mutually convenient location.
Interviews will likely commence early September.
These interviews will be transcribed by an external transcriber, for analysis. We can provide you with a copy of your interview transcripts, if you want.

If you choose to take part in this study, we would need to complete three short questionnaires either online or via post. The questionnaires will cover general demographics, quality of life and questions specific to CI users.

We will also need to obtain some audiological, case-history and contact information from your clinical file held at SCIP. Only the researchers in this study will access this information, and we will liaise with SCIP to obtain the information required.

In the interviews, there is a small risk that you might experience some emotional distress or stress in answering some of the questions. We can provide you with information on where you can further assistance if you need.

Participation is voluntary and you have the right to withdraw at any stage without penalty. You may ask for your interview tapes and transcripts to be returned to you or destroyed at any point. If you withdraw, I will remove information relating to you. However, once analysis of raw data starts in October 2019, it will become increasingly difficult to remove the influence of your data on the results.

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public without your prior consent. To ensure anonymity and confidentiality, all participants will be given code names or identifiers. Physical copies of the transcripts as well as hard copies of study-related information (including signed consent forms) will be stored in locked filing cabinets in the Department of Communication Disorders, which only the researchers will have access to. Electronic copies of the data only with other electronic study material will be stored on password-protected computers with the researchers only having knowledge of these passwords. Data will be kept at the Department for a minimum of 5 years, and longer if required by the journal which the results are published in. After this, raw data will be destroyed.
External transcribers will be required to sign a 'Transcription Confidentiality Agreement', and we can provide you with a copy of this if you wish.
A thesis is a public document and will be available through the UC Library.

Please indicate to the researcher on the consent form if you would like to receive a copy of the summary of results of the project.

The project is being carried out as part of the Masters of Audiology degree by Natasha De Jongh, under the supervision of Dr Rebecca Kelly-Campbell (Department of Communication Disorders, ph 03 3369 4519; rebecca.kelly@canterbury.ac.nz) and Dr Valerie Looi (Advanced Bionics Asia Pacific; Valerie.looi@advancedbionics.com). They will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked to complete the consent form and return to:

Natasha de Jongh

Post: Private Box 4800, Christchurch 8140

Email: natasha.dejongh@pg.canterbury.ac.nz

or

Dr Rebecca Kelly-Campbell
Post: As above
Email: rebecca.kelly@canterbury.ac.nz

Appendix E

Participant Consent Form

Department of Communication Disorders
Telephone: +64 3 369 4519
Email: natasha.dejongh@pg.canterbury.ac.nz

UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

The Patient Journey: From Hearing Aids to Cochlear Implants: A Retrospective Study
Consent Form for study participants

- ☐ I have been given a full explanation of this project and have had the opportunity to ask questions.
- ☐ I understand what is required of me if I agree to take part in the research.
- ☐ I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- ☐ I understand that any information or opinions I provide will be kept confidential to the researchers involved in this study, and that any published or reported results will not identify the participants. I understand that a thesis is a public document and will be available through the UC Library.
- ☐ I understand that the interview will be audiotaped, and externally transcribed, and that the transcribers will have signed confidentiality agreements.
- ☐ I understand that the researchers will need to access my clinical file and contact details held at The Southern Cochlear Implant Program (SCIP)
- ☐ I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years, or longer if the journal the study is published in requires this.
- ☐ I understand the risks associated with taking part and how they will be managed.
- ☐ I understand that I can contact the researcher [Natasha de Jongh; email: natasha.dejongh@pg.canterbury.ac.nz] or supervisors [Dr Rebecca Kelly-Campbell;, ph 03 3369 4519; rebecca.kelly@canterbury.ac.nz and Dr Valerie Looi; Valerie.looi@advancedbionics.com] for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)
- ☐ I would like a summary of the results of the project.
- ☐ I would like a copy of the transcript of my interviews.
- ☐ By signing below, I agree to participate in this research project.

Name:_____Signed:_____Date:_____

Email address:_____

☐ Please tick if you wish to be sent a report of findings.

Return your form to:
Natasha de Jongh
Post: Private Box 4800, Christchurch 8140
Email: natasha.dejongh@pg.canterbury.ac.nz

Appendix F

Pre-Interview Discussion and Verbal Consent

Patient Journey from Hearing Aids to Cochlear Implants: A Retrospective Study

Interview Guide

1) Opening the interview (5 mins)
   - Introduce yourself (your name, where you're from, your interest in this area).
   - Ask participant to introduce themselves.
2) Introduce the purpose of the interview and the study.
   - To better understand the process and experiences of adults who obtain CIs.
   - Stress the importance of wanting to hear their stories and gain an understanding from their perspective.
3) Give some guidance around expectations of the interview (length, type of questions and responses they can expect).
   - Interview should last around an hour.
   - You will take notes during the interview. This helps you stay on topic and follow-up where needed.
   - Will ask questions about how they felt and what they thought before and after they got their CI.
   - Will ask questions about how they feel their CI has (or hasn't) helped them.
   - Assure them their responses won't be identifiable, and we want them to answer openly and honestly.
   - Let them know that you will try not to interrupt them, but you may ask them to clarify things and may ask them to repeat information. This is to help you get a more complete understanding of their experiences.
4) Review the informed consent process
   - Ask if they have questions about the information sheet.
   - Ask if they have questions about the consent form.
   - Ask if they would like a summary of the findings (make sure box is ticked if they do).
   - Ask if they would like a transcript of their interview make sure box is ticked if they do).
   - Ask them to tick the consent box and sign the form.
   - Be sure to get them to provide their email address if they want a summary/transcript.
   - Make sure they keep a copy of their signed consent form and return a copy to you.
5) Obtain verbal assent for participation and permission to record interview.

TURN ON DATA RECORDER

Appendix G

Semi-Structured Interview Guide

1. To start, can you tell me a bit about your hearing history? This relates to the first stages (pre-awareness, awareness, movement). *What to listen for and follow-up on*:
    a. When hearing problems started
    b. When they first decided to get help for their hearing
    c. Their experiences with hearing aids – specific examples of what worked well, what didn't
    d. The impact of HI on their daily lives – specific examples
    e. The impact of HI on others – specific examples

NOTES: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

2. I'd like to get an idea of your motivation to get a CI. What was happening in your life that prompted you to start thinking about getting a CI? This relates to stage 1 (pre-awareness, awareness, movement). *What to listen for and follow-up on*:
    a. Striving back (going back to well-known life course)
    b. Their "tipping point" – specific examples of things, one big tipping point or lots of little things that added up over time?
    c. Who contributed to the tipping point?
    d. Why at that time?
    e. Why private?

NOTES: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

3. Can you describe the feelings and thoughts you had during this time? This relates to the transition to stage 2 (from the tipping point). *What to listen for and follow-up on:*
    a. Their emotional reactions
    b. Emotional reactions of others

NOTES: _____

4. How did you explore your options when you reached this point? This relates to stage 2 (mourning and exploring). *What to listen for and follow-up on:*
    a. Their perceived options before the 1st appt
    b. Their expectations and knowledge before the 1st appt
    c. *What did you most hope the CI would help with or provide*?
    d. How they made their rehab decision
    e. Perceived barriers – specific, pay particular attention to costs and funding options
    f. Perceived facilitators – specific, pay particular attention to costs and funding options
    g. Who helped them explore their options (HCP, family, ENT, GP, media)

NOTES: _____

5. Can you tell me about the time period between your candidacy appointment and your decision to get CI?
   What to listen for and follow-up on:
   a. Their emotions
   b. Their actions
   c. Sources of information
   d. What influenced them

NOTES: _____

6. How have you adjusted to life with a CI? This relates to stage 3 (rebuilding, restoring, stabilising). *What to listen for and follow-up on:*
   a. How/if they restored their identity
   b. How they feel they are currently functioning – specific examples (home, work, social)
   c. How life has/has not stabilised – specific examples (home, work, social)
   d. Their reflections on whether the CI has made a difference (home, work, social)
   e. Is the CI worth the cost?
   f. Would they recommend CI to someone in same situation and what advice would they give?
   g. If they had it to over again would they make the same choice?

NOTES: _____

Appendix H

AQoL-6D Questionnaire

AQoL-6D **(Data Collection Copy Simplified)**

Tick the box that best describes your situation as it has been over the past week

Q1 How much help do you need with jobs around your place of residence (eg preparing food, cleaning, gardening)?

- ☐ I can do all these tasks very quickly and efficiently without any help
- ☐ I can do these tasks relatively easily without help
- ☐ I can do these tasks only very slowly without help
- ☐ I cannot do most of these tasks unless I have help
- ☐ I can do none of these tasks by myself.

Q2 How easy or difficult is it for you to get around by yourself outside your place of residence (eg to go shopping, visiting)?

- ☐ getting around is enjoyable and easy
- ☐ I have no difficulty getting around outside my place of residence
- ☐ I have a little difficulty
- ☐ I have moderate difficulty
- ☐ I have a lot of difficulty
- ☐ I cannot get around unless somebody is there to help me.

Q3 How easy or difficult is it for you to move around (using any aids or equipment you need eg a wheelchair, frame or stick)?

- ☐ I am very mobile
- ☐ I have no difficulty with mobility
- ☐ I have some difficulty with mobility (for example, going uphill)
- ☐ I have difficulty with mobility. I can go short distances only.
- ☐ I have a lot of difficulty with mobility. I need someone to help me.
- ☐ I am bedridden.

Q4 How difficult is it for you to wash, toilet, dress yourself, eat or care for your appearance?

- ☐ these tasks are very easy for me
- ☐ I have no real difficulty in carrying out these tasks
- ☐ I find some of these tasks difficult, but I manage to do them on my own
- ☐ many of these tasks are difficult, and I need help to do them
- ☐ I cannot do these tasks by myself at all.

Q5 How happy are you with your close and intimate relationships?

- ☐ very happy
- ☐ generally happy
- ☐ neither happy nor unhappy
- ☐ generally unhappy
- ☐ very unhappy

Q6 Does your health affect your relationship with your family?

- ☐ my role in the family is unaffected by my health
- ☐ there are some parts of my family role I cannot carry out
- ☐ there are many parts of my family role I cannot carry out
- ☐ I cannot carry out any part of my family role.

Tick the box that best describes your situation as it has been over the past week

Q7 Does your health affect your role in your community (eg residential, sporting, church or cultural groups)?

- ☐ my role in the community is unaffected by my health
- ☐ there are some parts of my community role I cannot carry out
- ☐ there are many parts of my community role I cannot carry out
- ☐ I cannot carry out any part of my community role.

Q8 How often did you feel in despair over the last seven days?

- ☐ never
- ☐ occasionally
- ☐ sometimes
- ☐ often
- ☐ all the time.

Q9 How often did you feel worried in the last seven days?

- ☐ never
- ☐ occasionally
- ☐ sometimes
- ☐ often
- ☐ all the time.

Q10 How often do you feel sad?

- ☐ never
- ☐ rarely
- ☐ some of the time
- ☐ usually
- ☐ nearly all the time.

Q11 Do you normally feel calm and tranquil or agitated?
I am

- ☐ always calm and tranquil
- ☐ usually calm and tranquil
- ☐ sometimes calm and tranquil, sometimes agitated
- ☐ usually agitated
- ☐ always agitated.

Q12 How much energy do you have to do the things you want to do?
I am

- ☐ always full of energy
- ☐ usually full of energy
- ☐ occasionally energetic
- ☐ usually tired and lacking energy
- ☐ always tired and lacking energy.

Q13 How often do you feel in control of your life?

- ☐ always
- ☐ mostly
- ☐ sometimes
- ☐ only occasionally
- ☐ never.

Tick the box that best describes your situation as it has been over the past week

Q14 How much do you feel you can cope with life's problems?

- ☐ completely
- ☐ mostly
- ☐ partly
- ☐ very little
- ☐ not at all.

Q15 How often do you experience serious pain?

I experience it

- ☐ very rarely
- ☐ less than once a week
- ☐ three to four times a week
- ☐ most of the time.

Q16 How much pain or discomfort do you experience?

- ☐ none at all
- ☐ I have moderate pain
- ☐ I suffer from severe pain
- ☐ I suffer unbearable pain.

Q17 How often does pain interfere with your usual activities?

- ☐ never
- ☐ rarely
- ☐ sometimes
- ☐ often
- ☐ always

Q18 How well can you see (using your glasses or contact lenses if needed)?

- ☐ I have excellent sight
- ☐ I see normally
- ☐ I have some difficulty focusing on things, or I do not see them sharply. *E.g. small print, a newspaper or seeing objects in the distance.*
- ☐ I have a lot of difficulty seeing things. *My vision is blurred. I can see just enough to get by with.*
- ☐ I only see general shapes. *I need a guide to move around*
- ☐ I am completely blind.

Q19 How well can you hear (using your hearing aid if needed)?

- ☐ I have excellent hearing
- ☐ I hear normally
- ☐ I have some difficulty hearing or I do not hear clearly. *I have trouble hearing softly-spoken people or when there is background noise.*
- ☐ I have difficulty hearing things clearly. *Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said.*
- ☐ I hear very little indeed. *I cannot fully understand loud voices speaking directly to me.*
- ☐ I am completely deaf.

Tick the box that best describes your situation as it has been over the past week

Q20 How well do you communicate with others (talking, signing, texting, being understood by others and understanding them)?

- ❑ I have no trouble speaking to them or understanding what they are saying
- ❑ I have some difficulty being understood by people who do not know me. I have no trouble understanding what others are saying to me.
- ❑ I am understood only by people who know me well. I have great trouble understanding what others are saying to me.
- ❑ I cannot adequately communicate with others.

Appendix I

Nijmegen Cochlear Implant Questionnaire

Otolaryngology–
Head and Neck Surgery
Volume 123 Number 6

APPENDIX: NIJMEGEN COCHLEAR IMPLANT QUESTIONNAIRE*

*A native English speaker using forward-backward translation translated the NCIQ questionnaire.

Please answer the following 60 questions regarding the CI situation (use "not applicable" [N/A] only if none of the possibilities is applicable).

	Never	Sometimes	Regularly	Usually	Always	N/A
1. Can you hear background noises (toilet flushing, vacuum cleaner)?	☐	☐	☐	☐	☐	☐
2. Does your hearing impairment present a serious obstacle in your contact with persons with normal hearing?	☐	☐	☐	☐	☐	☐
3. Are you able to whisper if you have to?	☐	☐	☐	☐	☐	☐
4. Do you feel at ease in company despite your hearing impairment?	☐	☐	☐	☐	☐	☐
5. Can you hold a conversation in a quiet environment (with or without lip-reading) with one person?	☐	☐	☐	☐	☐	☐
6. Does your hearing impairment present a serious problem during your work or studies?	☐	☐	☐	☐	☐	☐
7. Can you hear the footsteps of other persons in your house (eg, in the hall or on the stairs)?	☐	☐	☐	☐	☐	☐
8. Does your hearing impairment present a serious problem in your contact with deaf persons?	☐	☐	☐	☐	☐	☐
9. Are you able to shout if you need to?	☐	☐	☐	☐	☐	☐
10. Does it bother you that you are hard of hearing?	☐	☐	☐	☐	☐	☐
11. Are you able to hold a conversation with 2 or more persons in a quiet environment (with or without lip reading)?	☐	☐	☐	☐	☐	☐
12. Does your hearing impairment present a serious problem in traffic?	☐	☐	☐	☐	☐	☐
13. Can you hear your own telephone or doorbell ringing?	☐	☐	☐	☐	☐	☐
14. Does your hearing impairment present a serious problem when you are with a group of persons (hobbies, sport, holidays)?	☐	☐	☐	☐	☐	☐
15. Are you able to make yourself understood to strangers without using hand gestures?	☐	☐	☐	☐	☐	☐
16. Do you become irritated if you cannot follow a conversation?	☐	☐	☐	☐	☐	☐
17. When you are in a busy shop, can you understand the shop assistant?	☐	☐	☐	☐	☐	☐
18. Does your hearing impairment present a serious problem during leisure-time activities?	☐	☐	☐	☐	☐	☐
19. Can you hear (not feel) the front door slam when you are busy at home?	☐	☐	☐	☐	☐	☐
20. Does your hearing impairment present a serious problem in your contact with the persons you live with (family/ partner)?	☐	☐	☐	☐	☐	☐
21. Are you able to adapt your voice to different situations (noisy environment, quiet environment)?	☐	☐	☐	☐	☐	☐
22. Do you avoid speaking to strangers?	☐	☐	☐	☐	☐	☐
23. Are you able to enjoy music?	☐	☐	☐	☐	☐	☐
24. Does your hearing impairment present a serious problem for functioning in the home?	☐	☐	☐	☐	☐	☐
25. Are you able to hear cars approaching in traffic?	☐	☐	☐	☐	☐	☐

	Never	Sometimes	Regularly	Usually	Always	N/A
26. Are you left aside in company because of your hearing impairment?	☐	☐	☐	☐	☐	☐
27. Can strangers hear from your voice that you are deaf or hearing-impaired?	☐	☐	☐	☐	☐	☐
28. Do you ask other persons to speak more loudly or clearly if they are speaking too softly or unclearly?	☐	☐	☐	☐	☐	☐
29. Are you able to recognize certain melodies in music?	☐	☐	☐	☐	☐	☐
30. Does your hearing impairment present a serious problem when you are shopping?	☐	☐	☐	☐	☐	☐
31. Can you hear soft noises (key falling, microwave beeping)?	☐	☐	☐	☐	☐	☐
32. Do you go places where your hearing impairment might present a serious handicap?	☐	☐	☐	☐	☐	☐
33. Can you make yourself understood to acquaintances without using hand gestures?	☐	☐	☐	☐	☐	☐
34. Do you feel anxious when talking to strangers?	☐	☐	☐	☐	☐	☐
35. Are you able to recognize certain rhythms in music?	☐	☐	☐	☐	☐	☐
36. Does your hearing impairment present a serious problem when watching television?	☐	☐	☐	☐	☐	☐
37. Can you hear (not feel) someone approaching you from behind?	☐	☐	☐	☐	☐	☐
38. Does your hearing impairment present a serious hindrance in your contact with persons who live in your neighborhood?	☐	☐	☐	☐	☐	☐
39. How often does it annoy you that persons can hear from your voice/speech that you have a hearing problem?	☐	☐	☐	☐	☐	☐
40. Can you understand strangers without lip-reading?	☐	☐	☐	☐	☐	☐
41. Does your hearing impairment present a serious problem at parties (eg, birthday)?	☐	☐	☐	☐	☐	☐
42. Can you hear (not necessarily understand) persons talking on the radio?	☐	☐	☐	☐	☐	☐
43. Does your hearing impairment present a serious problem when you are with friends?	☐	☐	☐	☐	☐	☐
44. Can you make contact easily with other persons despite your hearing problem?	☐	☐	☐	☐	☐	☐
45. Can you hear the difference between a man's voice, a woman's voice, and a child's voice?	☐	☐	☐	☐	☐	☐
46. Does your hearing impairment present a serious problem when dealing with formal matters (insurance, solicitor, municipal office)?	☐	☐	☐	☐	☐	☐
47. Can you hear when someone calls you?	☐	☐	☐	☐	☐	☐
48. Does your hearing impairment present a serious problem in your contacts with family members?	☐	☐	☐	☐	☐	☐
49. Are there situations in which you would feel happier if you were not hearing-impaired?	☐	☐	☐	☐	☐	☐
50. Do you feel it tiring to listen (with or without lip-reading)?	☐	☐	☐	☐	☐	☐
51. Does your hearing impairment present a serious problem when you go out or go on trips?	☐	☐	☐	☐	☐	☐
52. Can you hear voices from another room (eg, children playing, baby crying)?	☐	☐	☐	☐	☐	☐
53. When you are in a group, do you feel that your hearing impairment keeps persons from taking you seriously?	☐	☐	☐	☐	☐	☐
54. Does your hearing impairment undermine your self-confidence?	☐	☐	☐	☐	☐	☐

Otolaryngology–
Head and Neck Surgery
Volume 123 Number 6

	Never	Sometimes	Regularly	Usually	Always	N/A
55. Does your hearing impairment prevent you from sticking up for yourself (at work, in relationships)?	☐	☐	☐	☐	☐	☐

Please note: the answer categories for the following 5 questions are changed

	No	Poor	Fair	Good	Quite Well	N/A
56. Are you able to make your voice sound angry, friendly, or sad?	☐	☐	☐	☐	☐	☐
57. Can you control the pitch of your voice (high, low)?,	☐	☐	☐	☐	☐	☐
58. Can you control the volume of your voice?	☐	☐	☐	☐	☐	☐
59. Can you make your voice sound "natural" (so that is does, not sound like a deaf person's voice)?	☐	☐	☐	☐	☐	☐
60. Are you able to hold a simple telephone conversation?	☐	☐	☐	☐	☐	☐

Code book

Domain	Question	Recoding (6 score)
Physical		
Basic sound perception	1, 7, 13, 19, 25, 31, 37, 42, 47, 52	
Advanced sound perception	3, 9, 15, 21, 27, 33, 56, 57, 58, 59	27
Speech production	5, 11, 17, 23, 29, 35, 40, 45, 50, 60	50
Psychological		
Self-esteem	4, 10, 16, 22, 28, 34, 39, 44, 49, 54	10, 16, 22, 34, 39, 49, 54
Social		
Activity limitations	6, 12, 18, 24, 30, 36, 41, 46, 51, 55	6, 12, 18, 24, 30, 36, 41, 46, 51, 55
Social interactions	2, 8, 14, 20, 26, 32, 38, 43, 48, 53	2, 8, 14, 20, 26, 38, 43, 48

Appendix J

General Demographic Questionnaire

Demographic Information

1. Please indicate your gender.

☐ Male ☐ Female ☐ Gender Diverse

2. What is your current age? _____ years.

3. Please indicate your employment status.

☐ Full time ☐ Retired ☐ Student
☐ Not employed ☐ Full time house duties
☐ Part time
(number of hours per week:_____)

4. If applicable, what is your occupation?

_____

6. Please indicate your marital status.

☐ Married ☐ Single ☐ Divorced

☐ Widowed ☐ De facto partnership

7. How many people live in your immediate household, and who are they?

8. At what age was your hearing loss diagnosed? _____ years.

9. Do you know the cause of your hearing loss? Yes / No

If yes, what caused your hearing loss?

_____

10. How old were you when you were first fitted with hearing aids?

Left ear: _____ years.

Right ear: _____ years.

11. How much experience have you had using your current hearing aids?

Left ear: _____days/ months/ years.

Right ear: _____days/ months/ years.

12. What ethnic group do you belong to (please tick all that apply to you)?

New Zealand European

Tongan

Māori

Niuean

Samoan

Chinese

Cook Island Māori

Indian

Other, such as, Dutch, Japanese, Tokelauan. Please specify

Appendix K

Device and Audiological Information Sheet

Device Information

1. Date of cochlear implant (or scheduled surgery date)? _____

2. What type of cochlear implant/processor did your client receive (or will be receiving)?

_____

3. What speech processing strategy is/will be used?

_____

4. Are there any anomalies or issues with the device or electrode array (e.g. incomplete insertion, not all electrodes are active, kink in the array, etc.)? If yes, please provide detail.

_____

5. What type(s) of hearing aids is/was your client using pre- and post- implant (or will they use post-implant)?

Pre-implant: _____

Post-implant: _____

6. What prescription was used and/or will be used to fit these hearing aids pre- and post-implant (e.g. NAL-NL2)?

Pre-implant: _____

Pre-implant, were these hearing aids (circle one): Fit to target / under target / over target?

Post-implant: _____

Post-implant, were these hearing aids (circle one): Fit to target / under target / over target?

Audiological Information

NB: Please attach your client's pre-implant audiogram and if available, a post-implant unaided and aided audiogram.

7. What were your client's pre- implant speech perception scores (the ones recorded as part of their candidacy assessment)? Please only fill in the tests that were performed.

Words in quiet: _____% correct. Speech test(s) used: _____

Sentences in quiet: _____% correct. Speech test(s) used: _____

Sentences in noise: Speech test(s) used: _____.

Type of noise

☐ Adaptive: ____ SNR/dB

☐ Fixed level noise (SNR: _____ dB). _____% correct

Other tests: _____

8. What are your client's most recent post-implant speech perception scores? Please only fill in the tests that were performed.

☐ Not yet conducted (could you please forward this information to the researchers when you have completed these assessments).

Words in quiet: _____% correct. Speech test(s) used: _____

Sentences in quiet: _____% correct. Speech test(s) used: _____

Sentences in noise: Speech test(s) used: _____.

Type of noise

☐ Adaptive: ____ SNR/dB

☐ Fixed level noise (SNR: _____ dB). _____% correct

Other tests: _____

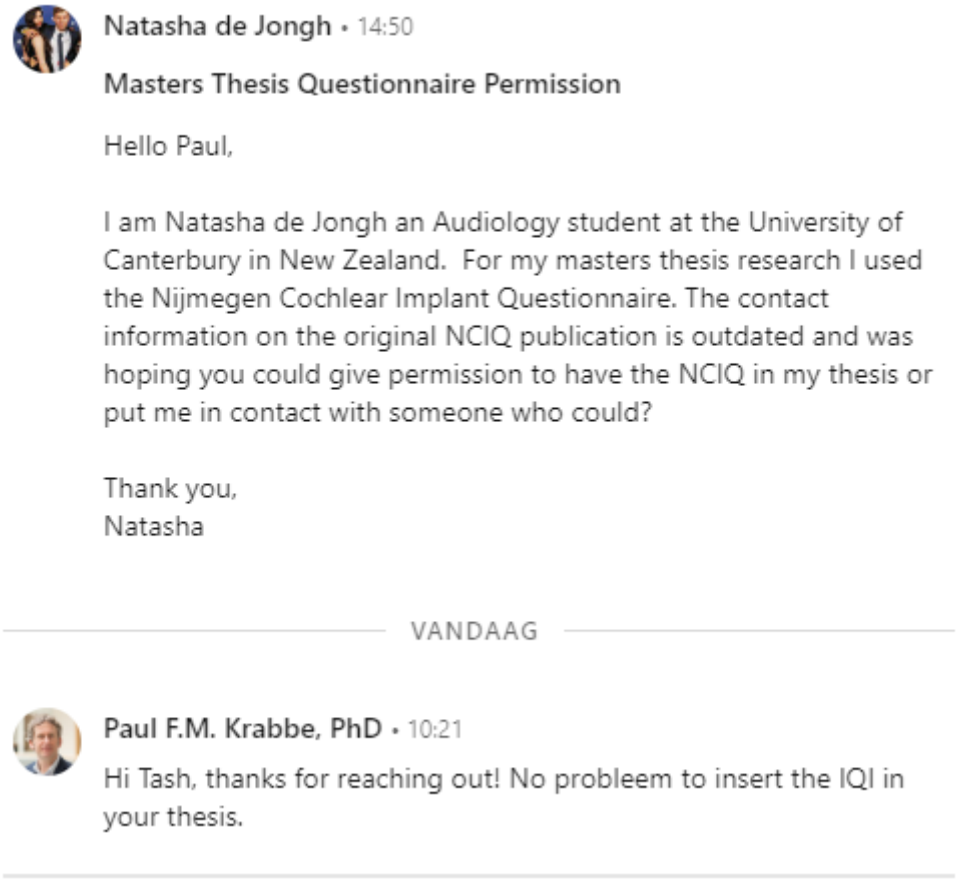
9. How long after switch-on were these tests conducted (e.g. 1 month, 3 months, etc.)?

_____

10. Any other comments? _____

Appendix L

Consent for Use of NCIQ



Natasha de Jongh • 14:50

Masters Thesis Questionnaire Permission

Hello Paul,

I am Natasha de Jongh an Audiology student at the University of Canterbury in New Zealand. For my masters thesis research I used the Nijmegen Cochlear Implant Questionnaire. The contact information on the original NCIQ publication is outdated and was hoping you could give permission to have the NCIQ in my thesis or put me in contact with someone who could?

Thank you,
Natasha

VANDAAG

Paul F.M. Krabbe, PhD • 10:21

Hi Tash, thanks for reaching out! No probleem to insert the IQI in your thesis.

Author contacted via LinkedIn.

Appendix M

AQoL-6D Registration Form and Consent

AQoL user registration form

Name of the study or project *	Patient Journey from Hearing Aids to Cochlear Implant: A Retrospective Study
Objective and brief description of the study *	In New Zealand there is limited funding for adults seeking cochlear implantation. Some who are cochlear implant candidates will privately fund for the device and implantation. This study aims to take an in depth look at the patient journey from hearing aids to cochlear implants using a retrospective qualitative framework. Better understanding of the patient journey can help develop a more patient-centred approach to care. The second aim is to help determine patients' sources of funding for private cochlear implants and therefore develop strategies to help others fund cochlear implants privately. This study undertakes semi-structed interviews with participants at 6 -18 months post switch on. Participants also complete three online/or mailed questionnaires to correlate with the interview data.
Please list the names of the Chief Investigators *	Natasha de Jongh, Dr Rebecca Kelly-Campbell, Valerie Looi
Name of the contact person *	Natasha de Jongh
Address *	☐ [redacted] New Zealand
Phone *	[redacted]
Mobile *	
Email *	natasha.dejongh@pg.canterbury.ac.nz
Which AQoL instrument do you want to register *	• AQoL-6D
In which country will the instrument be used? *	New Zealand
What is your study design? *	• Other
Expected start and finish dates of your study *	23/02/19 - 23/05/20
Anticipated number of respondents *	12
Which population are your investigating? *	• General adult population aged over 18 years
Will the study focus on Indigenous or Torres Strait Islander populations?	No
Gender of respondents *	• Males and females
Which disease categories will the study investigate? *	• Hearing impairment
Method of delivery of the instrument? *	• Post • Email/online
Method of completion of the instrument? *	• Filled in by respondent unassisted
Are you using this instrument as part of an instrument battery with other quality of life measures? *	• Yes
Are you willing to have any of the information provided on this form included in any reports about the use of the QoL instruments? *	• Yes
Are you willing to have your contact details made available to other reserachers working in similar fields? *	• Yes
The QoL research team is conducting ongoing research and validation of the QoL instruments. Would you be willing to provide de-identified AQoL data, together with basic demographic and health status information about your respondents? *	• No

Gang Chen [gang.chen@monash.edu]

To: Natasha De Jongh

Cc: Clare Austin [clare.austin@monash.edu]

Hi Natasha

Thanks for your email. I have checked your record and it seems you have put the information into a different registry.

The correct one can be found at: https://www.monash.edu/business/che/aqol/aqol-registration-form

After filling the form, you should receive an automatic email from the system as a record for what you have put in the system. You are free to use AQoL in your publication.

Best regards
Gang

Appendix N

National Institute on Deafness and Other Communication Disorders – Copyright Policy

(Figure 1)

The NIDCD provides external links solely for our users' information and convenience. When users select a link to an outside website, they are leaving the NIDCD site and are subject to the privacy limitations and policies of the owners/sponsors of that website. The NIDCD cannot control or guarantee the accuracy, relevance, timeliness, or completeness of information contained on a linked website. The NIDCD does not endorse the organizations sponsoring linked websites, and does not endorse the views they express or the products/services they offer. The NIDCD cannot guarantee that outside websites comply with Section 508 (Accessibility Requirements) of the Rehabilitation Act.

Review of Links

The links provided on the NIDCD website are reviewed at least each quarter, or more frequently as required by management and/or relevant regulation changes. The review is intended to ensure that links are still operational and valuable.

If you encounter a link that is no longer operational, please contact the NIDCD webmaster.

Link to Us

You are free to establish links to NIDCD online resources. In establishing such links, we ask that you avoid creating the impression that the NIDCD is endorsing or promoting any particular product or service.

Copyright Policy

Unless otherwise stated, the information on this site is not copyrighted and is in the public domain. It is free for the public to use, copy, and distribute. You may encounter documents that were sponsored along with private companies or other organizations. Those documents will have statements that protect them under U.S. and foreign copyright laws.

Some NIDCD web pages provide links to other websites that operate independently of the NIDCD. The NIDCD is not responsible for the availability or content of other sites. Permission to reproduce information at other sites may be required. The NIDCD does not endorse, warrant, or guarantee the information, services, or products described or offered at these external sites.

NIDCD content is also available through the HHS Syndication Storefront.

Logo Use

For information about using the NIDCD logo, please contact the NIDCD Office of Health Communication and Public Liaison or call 301-827-8183 between 8:30 a.m. and 5:00 p.m. Eastern time, Monday through Friday.

The No FEAR Act

The Notification and Federal Employee Anti-Discrimination and Retaliation (No FEAR) Act (Public Law No. 107-174) became effective on October 1, 2003. Its intent is to increase federal agency accountability for acts of discrimination or reprisal against employees. This act requires that federal agencies post on their public websites certain summary statistical data relating to equal employment opportunity complaints filed against the respective agencies.

In accordance with this act, statistical information relating to NIH equal employment opportunity complaints is available on the NIH Office of Equity, Diversity, and Inclusion website.

Information Quality Guidelines

The NIDCD is a trusted source of information on communication disorders. Read more about HHS's information quality guidelines.

Schedule for Publishing Information on this Website

We post information as available, unless otherwise required by law. Some areas of the NIDCD website are updated daily while others are updated less frequently.

Last Updated Date: June 5, 2017

Follow us on

Contact Us | Privacy | Accessibility | Freedom of Information Act | Site Map | Website Policies | Free Publications | Content Syndication

U.S. Department of Health and Human Services | National Institutes of Health | USA.gov—Government Made Easy

NIH... Turning Discovery Into Health®

National Institute on Deafness and Other Communication Disorders
31 Center Drive, MSC 2320, Bethesda, MD USA 20892-2320
Email: nidcdinfo@nidcd.nih.gov